



TIMES NEWSPAPERS

The Forgotten Illness

● Schizophrenia is the most common mental illness and fills more hospital beds than does any other disease. In every country one person in 100 suffers from it at some time in their life.

● In this country alone there are 250,000 sufferers; in the world, at least 17 million.

● Despite its prevalence, the disease has existed behind a screen of secrecy. Blame for the illness often has been placed on the family, while guilt and taboo have prevented them from seeking help.



THE TIMES CAMPAIGN ON SCHIZOPHRENIA

On December 16, 1985 *The Times* launched a campaign entitled "The Forgotten Illness". It had three aims: to sweep away the secrecy associated with schizophrenia; to stimulate research into the disease; and to stem the disaster about to hit the country through the closing of mental hospitals and the discharge of mentally-ill people into the community before there are adequate means to care for them. The campaign succeeded beyond all expectations. It

provoked thousands of readers' letters that showed the extent of the illness and the suffering it caused. It won the Campaigning Journalist of the Year Award for the writer, Marjorie Wallace, and it led to the formation the following year of the charity SANE (Schizophrenia: A National Emergency) to raise awareness, to help sufferers and their families and to carry out research for an eventual cure. Some articles from the campaign are reprinted here.

A SANE PUBLICATION

Overcoming the stigma



The forgotten illness

It is ten years since I first came across and wrote about the tragedy of schizophrenia. I had already through my time in television and journalism, seen the desperate situation of the thalidomide victims, the old and the handicapped, and the families who struggle to support them. But schizophrenia moved me even more deeply, perhaps because it is so close a threat, striking without warning young people at the peak of their promise, and because the scale of the problem is so daunting and unexpected.

Schizophrenia fills more hospital beds than does any other disease. But although it is so prevalent, it has existed behind a screen of secrecy. Families have not been prepared to admit that their child has become "mental". Doctors have not liked to diagnose the illness because of the effect on the parents.

Guilt and taboo have prevented relatives from seeking help, from becoming aware that there are so many others facing similar problems which, if shared, might be borne a little more easily. That situation was eased 15 years ago, when John Pringle, a journalist and businessman, wrote a letter to *The Times*. It produced many replies from the families of sufferers and led him to form the National Schizophrenia Fellowship, which has done marvellous work.

A year ago, when I wrote about the tragedy of schizophrenia for *The Times* and *The Sunday Times*. I was hopeful that, as John Pringle had done, we could help move forward public understanding of the disease and place more attention on the search for a cure. The article in the *Sunday Times* (p14) was historically the first shot, but it was Charles Wilson, editor of *The Times* who saw the need for a full-scale campaign and was prepared to give it space and support.

The most rewarding result was the enormous response the articles received and the support from professional bodies, psychiatrists, doctors, scientists and social workers fighting what they often felt was a lone battle against schizophrenia.

But the terrible situation described here is still not being alleviated. It is growing worse as the momentum of closure of the old mental hospitals gathers and as more and more seriously ill and institutionalized patients are thrust onto community services which are unable to care for them. This year I have travelled around Britain and found even more mentally sick people abandoned by the health authorities than a year ago. I found many sufferers who are getting no supervision or medical treatment, who cannot gain admission to the hospital and who are not given the medication they need.

Among the saddest are those victims who in rational moments sense their own suffering. On my travels I met Andrew Harrison, a young poet trapped by the disease. He described it thus:

There are many of whom the disposition of land and tide is more constant; For them there are moments of anxiety, suffused in the quiet joy of selves outlived and truths well tested... But I was always under the water Gasping for air and sunshine.

We at *The Times* hope you will respond to his cry. Marjorie Wallace, May 1987

The tragedy of schizophrenia: keeping When freed

In the first of a three-part investigation into schizophrenia, Marjorie Wallace reveals the burdens placed on relatives who are forced to care for the victims

THE TIMES 16 DECEMBER 1985

Schizophrenia, the forgotten illness, affects more than a quarter of a million people in Britain. It is not a "split mind" as it is commonly and wrongly defined; a better definition is bouts of mental anguish or insanity. It is one of the most frightening and disabling conditions that a human being can experience. We do not know what causes schizophrenia nor how to cure it. But attitudes towards mental illness have changed completely since the 1959 Mental Health Act. Before then, schizophrenics were regarded as mad, and conveniently locked away in the mental apartheid of the asylums. Since 1959 the doors have been opened and 67,000 inmates have been sent into the community.

For many, especially those who were hospitalized for the wrong reasons, lives have been transformed. But some are too ill to fend for themselves and the community does not yet provide adequate facilities to care for them. It is a tragedy of our times that there is nowhere for them to go. Some lead miserable lives in sordid boarding houses. Some are on the streets. Others may be put back with their families, whose lives they destroy. It is not an illness that attracts either much public support or sympathy.

Should having a schizophrenic relative be a life sentence for the entire family? *The Times* investigates the tragedy of schizophrenia in a series of three articles starting today.

Imagine a disease that fills nearly a quarter of the hospital beds in Britain, an illness that strikes down young people, mostly in their late teens and early twenties and destroys their lives at the peak of their promise, and from which two thirds never fully recover.

Imagine a disease that afflicts one in a hundred people at some time in their lives, most of them trying to live in the community, on the streets, in hostels or bed and breakfast places. About a third of our prison population suffers from the illness; many are there for minor offences caused by the illness. Thousands more live at home, a desperate burden on their parents and relatives.

This disease is schizophrenia. It is not much known or written about because there is so much shame and guilt and misunderstanding that it is almost taboo, surrounded by a conspiracy of silence, as used to be the case with cancer. It is so unfashionable that medical science has passed it by and very little money is spent on research into its causes and cure.

During the past six months I have interviewed 75 families of schizophrenics and sufferers from all parts of the country: from Devon and Cornwall to Edinburgh and Stirling in Scotland, from the countryside of Hereford and Hampshire to cities such as London, Leeds and Birmingham.

Psychiatrists, general practitioners, hospital administrators, directors of social services, community nurses and social workers have talked to me about the problems they face, as have the charities who pick up

their failures. And I have been shown the best and worst in the care offered to the mentally sick — from locked wards on the old asylums to modern cluster flats and landladies in the community.

But the most moving stories are those that I have been told by parents, husbands, wives, sisters or brothers who have sometimes spent 20 years or more in the daily anguish of watching a member of their family disintegrate in front of their eyes, realizing that they can do nothing to stop it.

They get little comfort or support from the psychiatrist, whose main concern is with the patient. He is often even reluctant to tell them, in the interests of the patient, the diagnosis or likely outcome. He may even add to the family's guilt, by saying they are to blame.

Nor is there much help from the social worker who regards the sick person, and not the family, as his client. Just as in recent child abuse cases, social workers have failed to visit, or made calls so superficial they have missed obvious neglect, so the families of schizophrenics have been given little worthwhile support. When matters become desperate and the victim becomes totally irrational, refusing medication and threatening violence, social workers are still reluctant to sign a section order to have the sick person admitted to hospital compulsorily.

Many families live in terror of their schizophrenic relative. One professional family in West London leaves food out on the doorstep for their son who sleeps rough. They dare not open the door. A widow in Southampton stays in the

dark every evening in case her 40-year-old son turns up, beats at the door and threatens her for money.

Another 70-year-old widow in Redruth in Cornwall is so terrified of her son's assaults on her that she has been forced to take out a private summons against him for "grievous bodily harm", although the shame of doing so is as painful as the bruises he inflicts. He is then committed under court order to be hospitalized for six months. She has been granted two such orders and is now seeking a third.

People who suffer from schizophrenia are not always aggressive: the majority is gentle and mild, but their disturbed perceptions can turn them against those members of the family who are closest. Yet these caring relatives are the very people who receive little comfort, advice or help from the health or social services.

The loneliness and horror of their experiences would make anyone want to cry out in pity. As I visited homes around the country from the most privileged to the poor, it was like being a war correspondent in peacetime Britain, reporting on the heartbreak of the bereaved and displaced. The plight of the schizophrenics and their families is a major tragedy. If present plans for closing hospitals and "dumping" people on their relatives or into scant or non-existent community care continues, it will be more than a disgrace. It will become the national disaster of the 1980s.

Ignorance about schizophrenia is profound. Almost everyone thinks of Dr Jekyll and Mr Hyde or of "split personality". It has nothing to do with that. It is better defined as periods of mental distress, so painful that the sufferers are unable to carry on normal lives.

6 The horror would make anyone cry out in pity 9

They feel invaded by strange and terrifying experiences which distort the way they see the world and prevent them relating to people. They withdraw and become emotionally cold and isolated. They feel their whole personalities disintegrate and lose their ability to concentrate or work. Often they stay in bed all day, too drained and blunted to move.

Schizophrenia seems to come in cycles. About one third of people who suffer a schizophrenic breakdown never experience another, but for the rest it is a lifetime's struggle against recurring attacks. Each one seems to take its toll, eroding the person's mind and character.

One third deteriorate so badly that they lose all touch with reality. As Dr Martin Roth, President of the Institute of Psychiatrists, says: "Schizophrenia is a destroyer of the beauty and individual colour of the personality."

The more bizarre symptoms experienced by some schizophrenics — are hallucinations and delusions — patently false ideas which are held with total conviction. One person thinks he is Jesus Christ, another that she is an aunt of the Queen. Those suffering from a more paranoid type of schizophrenia believe people are conspiring to kill them.

Most schizophrenics hear imaginary voices that admonish, cajole or threaten them. Often they argue with the voices, shouting to them to clear off. They believe sinister influences manipulate their thoughts and possess their consciousness. "I feel I'm in terrible pain," says Martin, a charming, intelligent young man of 30, who is persecuted by voices. "They torment me, telling me what a bastard I am. I don't dare sleep."

Faced with this barrage of voices, many schizophrenics are irritable and given to sudden rage and occasional violence. But the majority are quiet, slow and withdrawn, with blurred speech, sometimes using made-up words. Usually they have flattened emotions and dull wooden expressions. They are the most pitiful cases, depressed, often suicidal; people who have lost their will and become fragmented as though some cancer had invaded their personalities.

Andrew, who broke down while taking his post-graduate degree, now wanders the streets much of the day and night. "I feel a heavy black pressure as though one half of my brain is in darkness," he says.

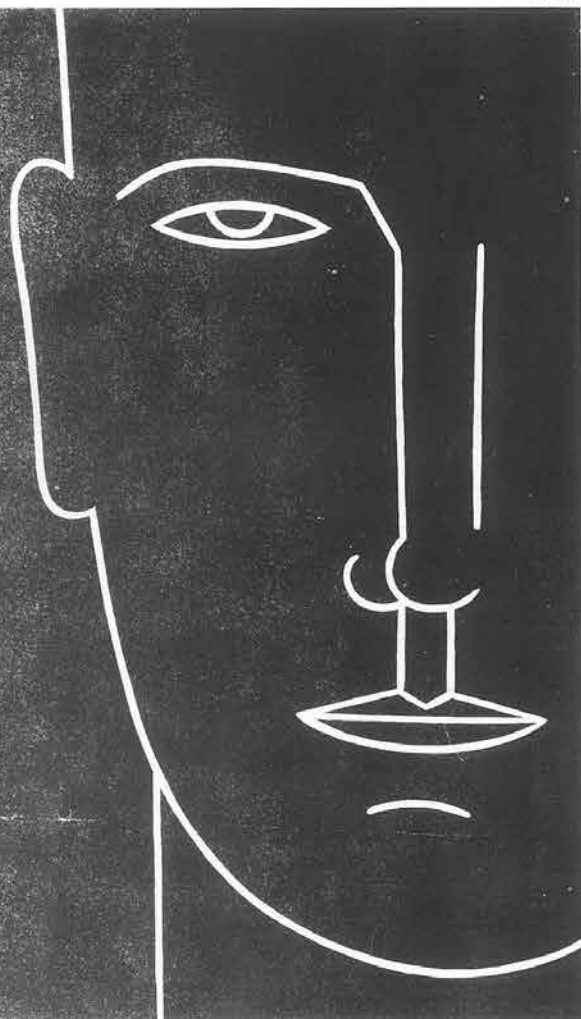
The symptoms of schizophrenia are most unpleasant for the victim, but he is often shielded by the nature of the illness itself from the full realization of what has become of him. For the families, there is no such protection. "It's like continual bereavement," says Andrew's mother. "The loss of your son's potential, the pain he goes through and the way people lose interest when he doesn't get better."

For many parents of schizophrenic children it is a lifetime's disappointment. John Blake has lived with his schizophrenic daughter for 30 years. She was 21 and a university graduate when she suffered her first breakdown. Now she is in her fifties and still lives a lonely, shattered life. "I don't know if she knows what she suffers from," her father says. "If I ever say anything about her, she becomes angry and tries to start a row. She is normally so apathetic, it seems to help. She could have been a

ing patients in the community can tear their families apart

om is a life sentence

Paul Leith



beautiful woman, she had such a pretty face. Now she looks drab and disorderly. It's difficult to love someone whose feelings seem so dead."

But even that is better than Ann Hill's ordeal with her son Angus. He had repeated breakdowns from the age of 16 and became increasingly violent. "He made us his prisoners in our own house and there was nothing we could do about it," says Ann. "Neither the doctors nor the social worker would put him into hospital against his will. It was only after he had hurled me across the room and banged my head against the wall that the doctors believed me and he was admitted to hospital."

But Angus was soon out again and started on the familiar "revolving door" pattern. He would return home, become violent and be admitted to hospital again. Home was the one place he turned to for help, but once there, he could not bear it. Eventually, he moved into a caravan and met his mother once a week in a local McDonald's.

The family cannot win. If they seek help for their disturbed relative, they are often told by doctors that they are being over-protective and that unsatisfactory family relationships are to

blame. "When did you last sleep with his father?" is a standard question to mothers. But if they close the door on their son or daughter, not only do they risk his or her suicide, they are also accused of neglect.

Moirra, a frail 71-year-old-widow, lives in a gaunt house on the outskirts of Stirling. In the Scottish tradition, she is not a woman who likes to seek help and she copes with her three sons' schizophrenia almost entirely single-handedly.

When one or other is desperately disturbed, they are admitted to the psychiatric hospital. But the hospital, the only one in a large area, is over-stretched and they are quickly discharged. The only help Moirra receives is a fortnightly visit from a community nurse who gives his injections to whichever brother is at home. The three men, in their thirties, sit in her living room. They are all shaking, ill, deluded and aggressive.

Moirra looks afraid and beaten. She dares not talk in front of them. "Why do you treat your mother like this?" I ask Charlie. "Because I hate her." "Why do you hate her?" He turns the volume of his cassette louder. "Because she flattened the earth."

CHRISTOPHER'S STORY

Boy who thought he could fly

Christopher was adopted at the age of eight months by Anthony, a glass engraver and his radiographer wife, Anne. He grew to be a tall and good-looking child with an IQ well above average and his family had high hopes for him.

Their faith was to be unrewarded. By the age of 16 he had made life at home intolerable by his bizarre behaviour. After a spell in Borstal, he drifted up to London and disappeared. Two years ago, at the age of 22, he turned up on the doorstep of his home in a Hampshire village.

"He was speaking in a strange accent, singing and dancing and hearing voices," says Anne. "He invaded our daughter's party and made sexual advances to all the girls. It was an awful scene."

The police took him to Park Prewett hospital where he was diagnosed as schizophrenic.

The hospital, under the new government policy, was anxious to discharge him into the community. He was placed in a hostel but soon refused medication and returned to his nomadic life in London. A few months later, he jumped from a third storey window, believing he could fly. He fractured both legs, and after casualty treatment made his way painfully back to Hampshire.

"I have never seen a human

being in such an appalling state," says Anne. "He was exhausted and in acute turmoil. We took him home but he was so ill he lashed out at us with his crutches." At first Park Prewett would not re-admit him, but Anne refused to leave until they accepted him back. Shortly afterwards, however, the hos-

pital suggested discharging him again.

Anne wrote to everyone for help: "They say they cannot treat him without his consent, but I do not think he is in a fit mental condition to decide. I know he is a great threat to society and I live in fear that he will do something awful."

No notice was taken. In February of this year, Christopher was discharged into a hostel without his parents being told. Twelve hours later, he severed both wrists and was returned to the hospital. "I am sure you will understand that Christopher is now an adult and we are under no obligation to let you know when he is being discharged from hospital or, indeed, if he is readmitted," wrote Dr Eileen Blackstock at Park Prewett hospital in reply to Anne's strong protests. "The hostel is a very supportive place... I do not think anyone could have anticipated these events."

The consultant continued to make plans for his rehabilitation in the community, but in March Christopher took events into his own hands. He walked out of the hospital with the intention of shooting himself and was caught stealing a car. He was imprisoned on remand in Winchester and sent under court order to a secure unit, where he now is.

"We feel tired and despairing in the battle to save him, but at least we can rest knowing he is safe and cared for," says Anne. "If only someone had explained more to us, we would not have felt such failures. We wanted him and loved him so much. Now I feel less terrified, I feel I could love him again."



Parents under pressure: Anne and Anthony

Scanning the brain in search of a cure

The Medical Research Council spends more than £100 million a year on medical research, of which £22 million is devoted to the neurosciences. Mental health receives about £5.5 million, of which more than £1 million is spent on drug addiction. Expenditure on research on schizophrenia is £532,000 a year or around £2 per person with the active disease.

But, whereas the "fashionable" diseases often have a great deal of research funded from other sources, such as the charitable trusts, there is virtually no extra money for schizophrenia research. The pattern is much the same in other countries, too. In the research laboratories, schizophrenia is very much the forgotten illness.

Very little is known about the cause of schizophrenia, and there is even controversy over whether it should be ranked as a disease. Some people still regard it as a psycho-social phenomenon brought about by interaction between the individual personality and his social environment. But nowadays most doctors and researchers think that it is caused by a disturbance in the biochemistry of the brain. That disturbance probably comes about by the triggering of an inherited predisposition, by stressed relationships, worry over exams or hormonal upsets such as after childbirth.

Research is being carried out in three areas. The latest developments in molecular genetics are now at a stage where it should be possible (though still exceptionally difficult) to analyse the genes of people suffering from the disease to find out where the inherited factor lies. It now seems probable that a number of genes are implicated, and that these genes individually, or perhaps in combination, also confer advantages on the people who carry them, otherwise they would have died out quite quickly. The first step is to identify families with strong inheritance of the disease, then to culture from cells in their blood, the complete range of genetic material they contain.

SANE has already made a contribution to this work by setting up a bank of immortalised cells from these schizophrenia-carrying families. Specimens are available for scientists to carry out their own research on these standardised samples.

There has also been an interesting development in the more traditional genetic studies with identical and non-identical twins. It seems that schizophrenia may be connected in some way with the inheritance of right- and left-handedness - that the disease is linked to the dominant side of the brain.

The main line of research is to discover what is going on in the chemistry of the schizophrenic brain. A starting point is the action of the "neuroleptic" drugs discovered in the 1950s and still used to control the acute symptoms of schizophrenia. These drugs block the messages passing between brain cells by occupying the "receptor" normally used by the chemical messenger dopamine. It is as though someone is preventing a telephone message being received by making the telephone permanently engaged.

But why does blocking these messages help schizophrenics? It is because their brain receptors are hypersensitive? Or do they have more of them? There is some recent work on the analysis of Schiz-

ophrenic brains which suggests this may be the case.

A new and exciting development in brain scanning, called the PET scanner, now makes it possible to see what is happening in a living brain: to watch a map of the changing chemistry of the brain while the patient is hallucinating. He is injected with a "labelled" version of one of the substances normally found in the brain (usually glucose). In the scanner the labelled substance emits atomic particles called positrons, and the exact three dimensional position of the labelled glucose is calculated by computer.

People are only just beginning to learn how to interpret the results of the PET scanner. In one study professional musicians were played familiar music. The motor areas of their brain lit up in the PET maps, showing they were interpreting the music as if they were playing it. When non-musicians were played the same music only the hearing parts of the brain were illuminated.

More than 20 teams are at work today in different parts of the world, learning the secrets of the brain with the PET scanner. There is only one machine in Britain (they cost £2 million each) which is at Hammersmith Hospital and is rarely available for schizophrenia research.

Another machine, the MRI (magnetic resonance imaging) scanner provides sharp pictures, reconstituted by a computer, of the detailed structures of the brain. Similar MRI scanners are now

RESEARCH AIMS

The task of the schizophrenia researchers is threefold:

- To determine what is the inherited factor of predisposition. If it could be found schizophrenia might be avoided, like Down's Syndrome, by early detection and the termination of pregnancies.
- To identify the triggering factors. If they were known, people at risk might be able to prevent the predisposition developing into the disease.
- To unravel the biochemical intricacies of the brain leading to the development of drugs, even more effective than the neuroleptics.

being used to monitor blood flow in different parts of the brain, showing the level of activity.

Although there are no breakthroughs yet, there are plenty of opportunities for schizophrenia research if there was the money and enthusiasm available to explore them. With such a shortage of research funds, SANE's Professional Advisory Committee decided it was essential to stop money being wasted by uncoordinated and overlapping research. Plans were therefore made to set up a centre of excellence to carry out research into schizophrenia, depression and other serious mental illness. The Centre, to be named after SANE's Patron, HRH The Prince of Wales, is to be built in Oxford where its researchers can benefit from contacts with the many scientists there engaged in brain research and neuroscience.

"In ten years time," says Professor Robin Murray of the Institute of Psychiatry, "these new techniques will have revolutionised our understanding of the brain." Perhaps they will also have brought to an end the agony of the schizophrenia sufferers and their families.

The tragedy of schizophrenia: where Through an

As mental hospitals close, Marjorie Wallace in part two of her investigation, describes the misery of patients allowed to drift without a proper home

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Dennis is on remand at Armley Prison, Leeds, charged with knocking over an old woman at Leeds City Bus Station. He is a gentle but severely damaged schizophrenic whom nobody wants. He has been ill since his early twenties, when he was starting on a musical career. For 10 years he was in and out of mental hospitals on the crazy carousel of the open door treatment policy.

He was turned out of one bed-sitter or hostel after another, eventually ending up in the Camberwell reception centre in London. He has been in court on a string of minor offences for altering drug prescriptions and in one case for stealing a bottle of aftershave - to drink.

The present way of treating people like Dennis is to let them live in the community backed up by a network of services provided by local and health authorities. It is intended that they go once a week to the local hospital out-patients department for medication (assuming they remember the appointment); that social workers will help them with problems; a day centre and sheltered workshop will provide a social life and an occupation; and if they have no relatives to live with, they will be found a place in a flat shared with other mentally ill people, a group home, a hostel or lodgings with a caring landlady.

Does this work? Portsmouth is a model area being created on a "patchwork" system. The town will be split into five areas, each having a day centre with two crisis beds. There are 43 community psychiatric nurses, the highest number per population in the country. St James's, the area's main psychiatric hospital has been slimmed down to 400 beds and the plan is to reduce it to about 150 for long-stay patients, mainly elderly.

Portsmouth Housing Association has only six group homes for those with chronic mental illnesses. "For most ex-patients it's homelessness, night shelters or whatever bed they can find in the private sector," says Terry Hammond, who has been involved in 30 different schemes for housing the mentally ill. "In the last few years, there's been a vast shipment of patients from the hospital who then become lost in the community. No statistics are kept and they drift from town to town."

The really sick and needy, when they leave hospital, stream to Southsea, an old-fashioned seaside resort full of cheap boarding houses. Many are now being used as homes for the mentally sick as good money can be made: the Department of Health and Social Security pay up to £110 a week per person for registered accommodation and £55 unregistered. A condition of registration is that a trained nurse be available 24 hours a day.

The money is so attractive that some psychiatric nurses have left the demoralized atmosphere of the hospital to set up their own lodging houses. They have the advantage that they can select the least troublesome patients, even making arrangements with them before leaving the wards. There are stories of nurses "poaching" patients from each other to keep their new homes filled. "Some places are good," says Ken Preston, Portsmouth's rehabilitation officer, "but some are just mini-institutions where there is even less for the patient to do during the day."

I found Michael, who is 70, living in an unregistered home in Byerly Road, Portsmouth with 12 other ragged, grimy, elderly men, a number of them mentally ill. The house has three bedrooms and a lounge, which is also used as a sleeping area. Michael shares his bedroom with three others: he has the top place on a bunk bed. The landlady, Mrs Walker, is in her seventies and bedridden, but she employs Peter to run the house. "You can conduct your business elsewhere," he said, exposing a tattooed arm as he threw me out.

Michael moved to the house about 10 years ago after discharge from the hospital. His treatment is a fortnightly injection administered by a community nurse. He would like to leave, but does not know how. "I'm frightened of Peter," he whispered on the doorstep.

John, an ex-charge nurse from a psychiatric hospital, applied for transfer to become a community nurse. He is disillusioned by what he has seen, but is afraid to talk. "I am appalled by the places I have to visit," he says. "At least in hospital these people had some dignity and something to do. These places are so filthy and lonely. Last weekend I took a meal to an elderly mentally ill woman. She

didn't have a piece of cutlery to eat it with. I had to borrow from next door. The people in charge don't want to hear these stories. Everybody wants to believe that community care is progressive."

Last year the local authority investigated Southsea boarding houses. So far, out of 90 houses inspected by the environmental health officer, 76 have failed to fulfil the minimum standards for houses in multiple occupation and 28 have been recommended for prosecution.

In large cities, which have an irresistible attraction for schizophrenics, yet no money to provide facilities, the situation is worse. The Moseley district of Birmingham is a gathering place for ex-patients. At the Kinmos centre they can drop-in for tea during the day but on Sundays there is nowhere to go. "The level of

after care for patients is non-existent," says Derek Hall who runs the centre. "You can see some of them going back and forward across the road counting their steps. They've nothing else to do. It's very sad."

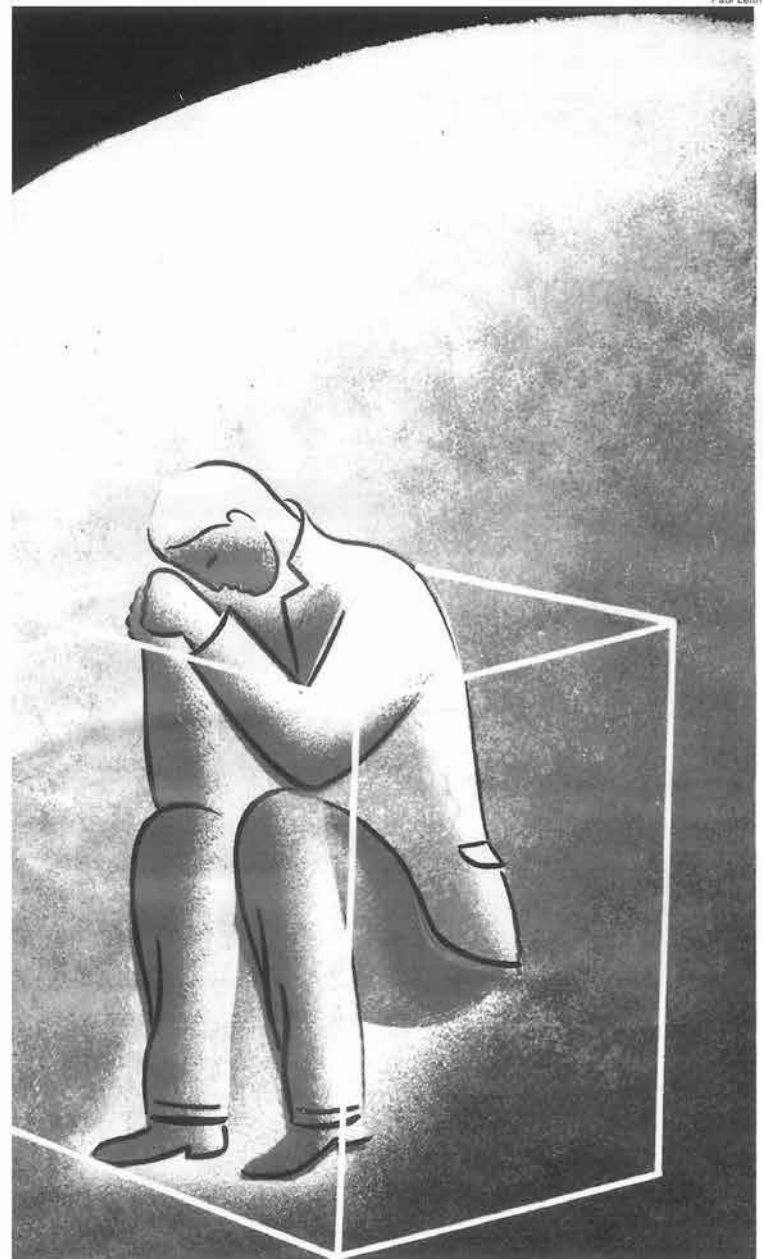
He is also concerned about the bed and breakfast places where ex-patients are sent. "Some of these are deplorable. The police had to rescue an old man who had been locked up all weekend by his landlady. He had not been fed from Friday to Monday though the DHSS pays for him to have a meal a day. The landlady controlled his benefit book. The social services could do nothing as it was a private home and they have no right of entry." I talked to two young men, one who still lived there and one who had left. They confirmed the stories but when I went there the door was shut in my face.

A few streets away Mrs

re the progressive vision of community care falls down

open door to despair

Paul Leith



DAVID'S STORY

Sick boy no one would help

A hunched figure shuffles down the corridor of Laburnum ward, the locked area for the most disturbed patients in Napsbury hospital, near Watford. He wanders among senile old men with stained jerseys and blank faces. His mother stands helplessly, as he crouches on the floor and looks at her with a threatening glare, his muscles tensed as though about to spring for her throat.

It is a disturbing experience and impossible to believe that this angry, emaciated creature is the sensitive, scholarly-looking young man I had seen in the photographs. A young Chinese staff nurse taps him gently and asks that he speak to his mother. David gives a slow hissing sound and turns away.

At 28 David is a pathetic figure, his body twitching and shaking, possibly the result of years of medication. This locked ward is the best care he has yet received for the illness which has destroyed both him and his family for 12 years.

"It was very sudden. He had taken eight O levels. He was a bright, normal boy living with us, his elder brother, and two younger sisters," his mother says. "Then he began to say strange things about how he had a devil inside him telling him what to do. He would get a look of terror in his eyes, as though he were possessed. We were frightened by his expression."

David began to suffer from hallucinations and his parents took him to the doctor, and he was taken to Shrodells Psychiatric Unit at Watford.

The worst experience was the night David discharged himself from hospital, climbed a drain pipe at his home, broke a window and began to ransack the house, taking out drawers, and holding his family hostage.

"They always made us feel it was our fault. We were the sick ones," she said. Shrodells refused to take him as an inpatient and they advised the family to force him to leave home. Jean breaks into tears as she recalls how he walked away with a list of charities for the homeless in his hand.

For the next year David slept in cardboard boxes under

Charing Cross arches. It was 1981 and one of the coldest winters on record. In 1982 he was arrested for stealing a T-shirt, spent six weeks on remand in Brixton and appeared before Watford magistrates. His lack of care shocked Mr Edward Kennedy, the chairman of the bench. The court was told that the staff at Shrodells Wing had said he needed treatment, but they could not cope with him there. They also heard that although the doctor at Brixton Prison felt he was ill, he did not think he was sufficiently ill for an order to be made to keep him in hospital under the Mental Health Act.

Mr Kennedy said "It is quite irresponsible that he should be thrown out for this court to deal with because of a difference of opinion in the medical world. If he was knocked down by a bus he would get instant treatment." David was freed on bail but again he had nowhere to go.

It was the Church Army that came to his rescue. When he was in an acute schizophrenic episode, an Army official took

him to Shenley hospital near St Albans and threatened to chain himself to the railings if David was not admitted.

Eight months later he discharged himself and disappeared. Since he was a voluntary patient, the hospital was not obliged to inform anyone or alert the social services. His parents reported him as missing and six weeks later they received a letter from him from Winslow Green prison, Birmingham. He had fallen asleep on the train and ended up in Rugby with no cash, only a cheque from his benefits that the hospital had given him; he had stolen a 38p pork pie from the station buffet. The judge ordered that he should receive treatment in a psychiatric hospital for a minimum of six months.

"For the first time in many years I can sleep knowing that he is safe," says Jean. "He is known as the boy no one wanted to help. If I tried I was called a smothering mother, stopping him from being independent. But he was just too ill to grow up."



David in less troubled times before illness took its grip

Violet Harley runs the Clare Hotel for 36 ex-mental patients, many severely dependent. She charges £70 a week but she has trained staff and looks after her guests carefully. She is worried about bed and breakfast homes such as the one described above. "This sort of work is wide open to abuse and can attract the wrong people. There was one woman I fetched from prison and looked after at my hotel. She stole and lied and I asked her to leave. She immediately set up her own home for the mentally ill."

The situation is worse in London. In Greater London in 1981, 23,972 people were discharged from mental illness hospitals; only 417 were taken into local authority residential care. Seven London boroughs do not have a home or hostel to care for the mentally ill.

Everybody in the field agrees that community care has not worked. Most

blame lack of funding and bridging finance (to look after a mental patient in the community is more expensive than in hospital); others say that the concept did not take account of a proportion of patients who would never find a welcome in the outside world. The old mental hospitals are due to disappear, the buildings and land are being sold, but the alternatives promised in government white papers have, for the most part, not been built. Dr Rosalind Furlong, consultant psychiatrist at Friern hospital, says: "The danger is that the hospital will discharge a patient into the community without knowing if he is able to cope. Then, if he is thrown out of every hostel or lodgings, there will be nowhere for him to return." The hospital beds will be closed and the land turned into housing estates. "It looks a better deal for the patient initially, but in fact

he has far fewer rights and less security than he did before."

The National Association for Mental Health (MIND), the pressure group which has been in the forefront in promoting the hospital closures, now admits something is wrong. "There is a looming crisis," says Christopher Heginbotham, director of MIND. "What is happening is a disaster. There is very little community care provided. Nowhere is there a comprehensive service reflecting our objectives to help people rebuild their lives."

So where are the missing patients? Most will have joined or tried to join their parents at home. Some will be in lodgings and some are wandering the streets and sleeping rough. The police are disturbed by the numbers they take under section to hospital who are then turned away. "It's a race as

to who gets back to the station first, the patient or us. But where can he go? A police cell is not the right place for a sick person. There was a recent case where seven hospitals serving the London area refused to accept a violent young man," says Inspector Peter Dowse, who is responsible for the policy adopted by the Metropolitan Police towards the mentally ill.

"I started to talk to some of these people in the streets," says Dr Malcolm Weller, consultant psychiatrist at three North London hospitals. "I found almost all of them had fallen out of any kind of medical care. The new policies have created a large group of mentally ill people who are also physically ill, scraping out dustbins and sleeping on park benches. However inadequate hospital treatment is, it is better than this." Inevitably, many end up in prison.

"While they're closing 30 hospitals, they're planning to build 14 new prisons," says Dr Weller.

Meanwhile, the momentum of hospital closures continues, and more chronically sick people are thrown into an unwelcoming world.

As the pressure on hospitals continues, they are being forced to discharge patients without any provision. Gladys is due to leave the Royal Free in London where she has been acutely ill following a post-natal breakdown. On learning that she was suffering from schizophrenia, the father of her baby gave it to a relative and refused to take Gladys back. "We can get no place for her until she is proved technically 'vulnerable homeless'," says Joy Pappenheim, the social worker involved. So Gladys, depressed and afraid, carrying all her possessions, will leave the

warm wards to join the homeless persons queue. If she ever leaves the lodgings offered, however unsuitable, she will be "voluntary homeless" and no one will be responsible.

For some ex-patients, this prospect is too much. Michael became a schizophrenic at 23, throwing up his career as an artist. He spent several turbulent years in and out of hospital, and terrorized his family. "He used to line up the knives and point them in my direction wherever I moved," his mother recalls. "He even threatened us with an axe." He was admitted to Friern hospital in North London but was discharged because it was no longer hospital policy to retain people who were unlikely to improve.

Six weeks later Michael's mother heard that his body had been found in a river near where the family had lived when he was a child.

The tragedy of schizophrenia: how the law has left sufferers to de

A patient's cry – can nobo

In the last of the three-part series on schizophrenia, Marjorie Wallace looks at the implications of the 1983 Mental Health Act and the effect it had on one man's life

THE TIMES 18 DECEMBER 1985

It is a squally autumn evening. Mist and rain creep in over the west Cornish cliffs, obscuring a group of mourners who cluster around a skinny almond tree. A plaque is nailed to its bark: "To the memory of David Royston Green 1957-1985." The tree has been planted beside David's grave in the churchyard, which forms part of the garden of the house in which he was brought up and spent most of his last two despairing years.

Later that evening, the same group is sitting in the Forum Room of Redruth's Penventon Hotel. A grey-haired woman in her seventies presses the switch on a tape recorder and the guests listen to a muffled recording of Beethoven's fifth piano concerto, David's favourite music. There are readings from Shakespeare and John Clare. Then a psychologist delivers a lecture on "The care of those suffering from schizophrenia" followed by a discussion entitled "Its availability in Cornwall."

David, the adopted and only son of Roy and Blanche Green, suffered from schizophrenia, a form of recurring mental anguish which destroyed his will and personality and led him to commit suicide. But his mother is convinced that his death was due not only to his illness but to neglect by society and particularly by the health and social services which failed to care for him in his hours of need.

Blanche Green looks towards the rows of empty seats that have been set out for all the health officials, the social services, the psychiatrists and the nurses whom she has invited to share in the mourning of her son's death. She sent out 50 invitations. No one other than close friends and family has come. "I considered it inappropriate to continue my involvement in a memorial setting," Richard Lingham, director of social services told me later. Others gave excuses or did not reply.

David first showed signs of his illness two years ago when he was 26. He was working as a motor mechanic and he began to feel uneasy with his workmates, believing they were mocking him. He split up from his girlfriend and isolated himself from former friends and his family. His mother, a retired health visitor, had left home to take a job as a nurse/companion and was

unaware at first of what was happening.

"He came home and lived in an old chalet we had in the garden," says his father, Roy. "He stayed there all day, never drawing back the curtains. The place was filthy and disordered. He didn't like it at first because it overlooked the graveyard. But then he took up interest in the occult and astral projection. He believed he could see a nun who used to live here. He had been a gentle, sympathetic young man and very popular with the girls. Then

Someone has to try to break the private hell of indecision

he started calling his last girl friend a witch." He began to quarrel with his normally laconic father, shout to voices he heard in his head and disappear. Sometimes he was found by the police, sleeping in an old car or walking in the country.

On the one or two occasions he was persuaded to go to a doctor, he was charming and coherent and not apparently in need of help. The doctor refused to talk to Roy or Blanche about David unless he was present too. When they did find help, Blanche was told she was the cause of the illness. David was happy. It was she who was doing the crying.

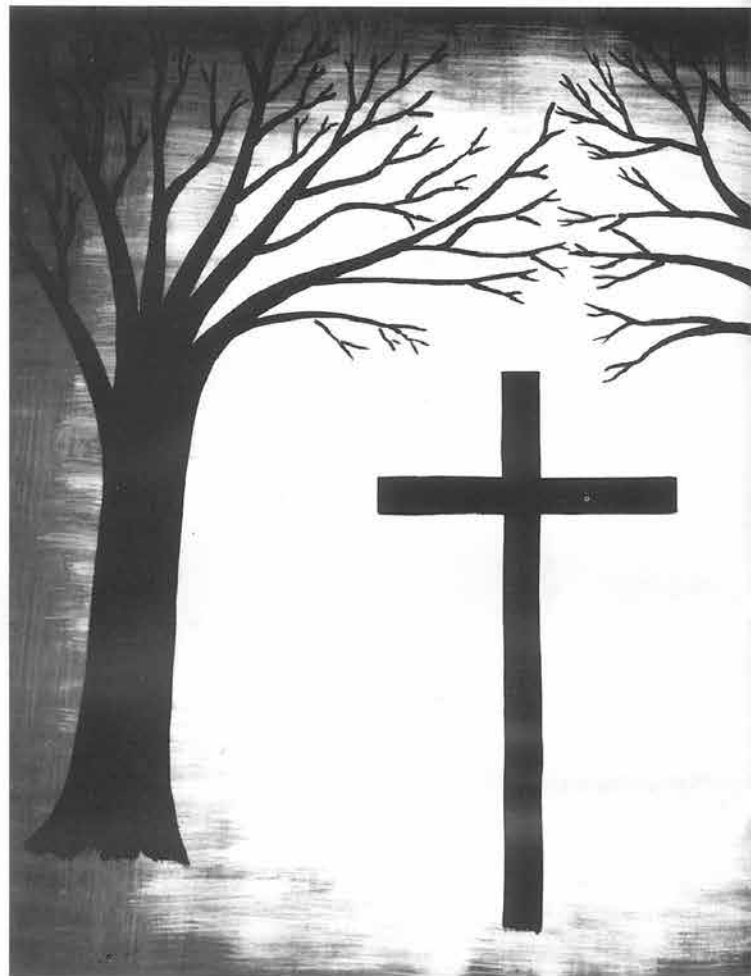
By the end of last year, David was severely ill, apathetic, frightened and subject to tormenting depressions, exacerbated by his failure to keep jobs or friends.

"February 5," he wrote in his diary. "Very depressed. I do not understand the circumstances of my illness. I am at a loss to know which is the right direction. I don't understand why I feel so alone or appear to be so alone. This loneliness is the thing that will KILL me in the end."

He received some out-patient treatment from a psychiatrist but when his mother tried to get him admitted to hospital, he was taken in for a night and then told by a social worker to find his own digs the following day. He was advised to look in *Yellow Pages* and if he needed help, he must get himself to a doctor. As Blanche Green pointed out, this was precisely the kind of move his illness prevented him from making. She felt that if he were to be supported in the community it was the duty of those responsible to seek him out. "Someone had to break the private hell of his indecision," she says.

The professionals stuck to their moral code. If David did not seek them out, then he had the right to be mad and untreated. "It's a question of individual liberty," says Richard Lingham. "Some people prefer to live out the period of their illness in a disorientated and, at times, unhappy state as free individuals in the community. The balance is between community care and policing. David Green's sad case exemplifies some of the many problems involved in making judgements within the philosophy of the Mental Health Act 1983."

But he also admits that Cornwall, a rural area more than 100 miles long, is so impoverished for services that it would be impossible for social workers, doctors



or the 14 (only eight at the time of David's death) community psychiatric nurses to be available for every emergency. The nurses work on weekdays only; at weekends there is only one psychiatrist on duty for the whole of Cornwall and there is no other crisis intervention service. GPs are reluctant to be involved, so often the only help available is from the police.

Even then, if the sufferer has not actually harmed himself or his family, or committed a breach of the peace in a public place, it is treated as a domestic matter.

David was not violent and in his attempt to keep his dignity and independence, did not always ask openly for help. He became more disturbed, rejected a place at a day centre offered him, and slept in his car and

then in a caravan at Launceston, nearly 100 miles from his home. The week before Easter this year he was turned down as being too unwell to take up a place on an industrial rehabilitation course. He telephoned his mother with the news of the disappointment and she alerted his social worker in Launceston.

By Wednesday of that week, no-one had visited David and he told neighbours: "No one can help." He failed to keep an out-patient appointment with the psychiatrist in Redruth. After further pressure from Blanche Green, the social worker Henry Stanbury called but judged that no further action was necessary. "David did not manifest the nature of his feelings or intentions," wrote Mr Lingham. "But if he had done so, Mr Stanbury and his medical colleagues were ready and willing to respond."

Blanche Green says that David did tell his family but their warnings to the authorities were ignored. On Easter Monday David was found dead in his car on Bodmin Moor. He had died from carbon-monoxide poisoning. "He was pathetically grateful if anyone did visit him," says Blanche Green. "They waited. He died. It was wilful neglect."

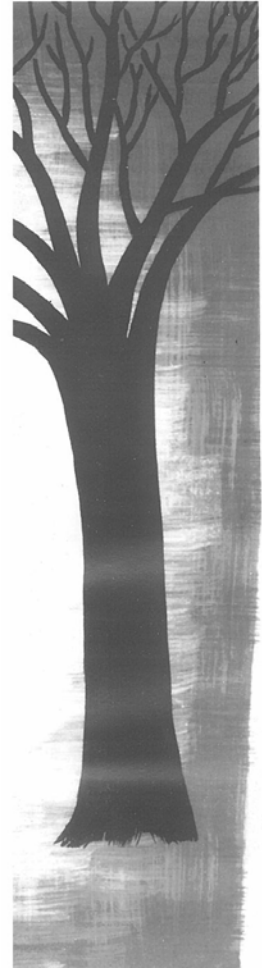


Life and death: Mrs Blanche Green plants a tree in the local churchyard in the memory of her son David (right), a schizophrenic who killed himself with exhaust fumes from his car



side their own future dy help?

Paul Leith



THE LEGAL POSITION

Community care has been government policy since Enoch Powell, then Minister of Health, introduced the 1962 Hospital Plan for the running down of the old asylums and the shift of resources from hospitals to local authorities. A series of white papers and consultative documents followed, outlining plans of how this transition should be made.

But the promised alternatives have been slow to materialize. Local authorities are not statutorily obliged to provide accommodation (except for the vulnerable homeless) or day care and, under current financial pressures, few have been willing to devote more than token resources. In a strongly-worded report in February this year, the House of Commons all-party Social Services Committee warned: "The pace of removal of hospital facilities has far outrun the provision of services in the community to replace them."

Mr Barney Hayhoe, Minister for Health, said yesterday: "The mentally ill deserve better than to become unwilling long-stay patients in large wards of run-down Victorian institutions. Community care can, and should, provide a more humane and civilised way of offering support to many people. It requires careful individual assessment and effective planning by different agencies and it is essential that it is followed through so that there is no danger of people getting 'lost' in what can be a hostile outside world.

"Sadly, mistakes are still being made and I do not defend them. But it can work when it is pursued with enthusiasm and commitment. That is what I am urging health authorities to do in collaboration with local authorities and voluntary organizations."

episodes since the birth of her third baby. She was paranoid and, during an acute phase, would no longer attend the out-patient clinic.

Just over a year ago, she locked herself up in her home and refused to answer the door. Her married daughter, Jane, who lived 100 miles away, wrote letters asking the doctor and social services to intervene. When Jane eventually arrived and knocked down the door, she found Gladys half-starved and with badly ulcerated legs.

There was filth all over the carpet. Also on the carpet were letters from the out-patient clinic reminding Gladys of her missed appointments, and notes from the community nurse to say that she had called but, on having no reply, had gone away. "You don't believe that such a story could happen in this country until it hits you," says Jane. "My mother died because no one would help."

LAST WORDS

A poem written by David, the bright, normal boy whose surrender to schizophrenia was described yesterday, sums up his 12 years of misery:

Just standing by the door
Waiting
Waiting interminably
For
Just something . . .

The case of David Green challenges the ethics of the new approach to mental health. It is based on the freedom of the individual to determine for himself whether he wants help or treatment. But the fundamental difference between a mental illness and a physical one is that the illness itself can deprive the individual of the ability to make a rational judgment. A doctor would not hesitate to provide help for someone knocked unconscious in a motor car accident, or who went into a diabetic coma. Should not schizophrenics be given the same opportunity of survival?

Since the amendments to the Mental Health Act 1983 have been implemented, doctors are finding it increasingly difficult to treat their patients. "It's very frustrating," says Dr. Rosalind Furlong, consultant psychiatrist at Friern hospital, London. "The definition of the illness is that you don't have insight, but we have to wait until a patient is really ill or becomes a danger to himself or others before we can intervene. Sometimes it's too late."

Many doctors and care workers do not even attempt to treat a patient who does not want or accept help. Gladys Bamber from Plymouth in Devon, suffered from schizophrenic



THE TIMES 19 DECEMBER 1985

EASE A TRAGEDY, STOP A SCANDAL

In the last days of its bicentenary year *The Times* has this week received some of the most moving responses that we can ever recall to a series of feature articles. Schizophrenia is a disease that comes and goes without warning. It attacks promising teenagers and those fulfilled in middle-age. To the one per cent of the population who suffer its affliction the disease often denies insight into their own conditions. But to judge from what we have heard and published in the past three days it is almost as if it were the other 99 per cent which lacked the insight into schizophrenia. It has indeed been the forgotten illness.

To put a continuing tragedy to the forefront of our readers' minds is one thing. To suggest how it may be alleviated is much harder. Schizophrenia is on one level simply a disease — with causes that are generally accepted to be biochemical and effects that are as cruelly clear to those close to the sufferer as they are so often consciously concealed from everyone else. But on another level schizophrenia is a dark mystery. Its sufferers are sometimes able to live what we know as normal lives, sometimes violently ill, uncontrollably ill, unrecognizably ill.

The duality of the condition has excited artists and writers who have seen it as a paradigm of the human condition itself. It has also excited intellectuals — most notably R. D. Laing and his followers — who have used it as a stick to beat the western organization of family life. To those who examine it closely the world of schizophrenia is like a battlefield of fear and elation, of blood and courage and of sometimes warring ideologies each with their own vision of the right on their side.

Behind this fog of confusion it is clear that public policy towards schizophrenia is also in a mess; and it is the very alternation between sickness and health that is at the heart of the problem. Schizophrenia requires two distinct varieties of care: specialized care inside institutions and specialized facilities outside in the community. It needs the consent and understanding of the public both to pay for such care and, when the care takes place in the community, to co-operate in it too.

That consent — never as strong as it should have been — is now under threat from the very execution of policies that were designed to improve it. Schizophrenia — like all forms of mental illness — is less of an utter taboo than it was. The efforts of charities like MIND, the National Schizophrenia Fellowship (NSF), the Richmond Fellowship and others, have shifted public perceptions of mental illness. So has the commitment of every government since the early 1960s to community care for the mentally ill, after Enoch Powell as Minister for Health first eloquently condemned Britain's isolated, Victorian lunatic asylums to eventual extinction.

But Conservative ministers and organizations like MIND are not natural allies. Despite the apparent similarity of their commitments against institutionalization and in favour of community care both have forces behind them that would need little encouragement to be at each others' throats. MIND, at its recent conference, passed a resolution that talked of its opposition to "involuntary incarceration" and the use of "brain damaging and addictive drugs", representing as they do in MIND's view "an unacceptable form of institutionalized violence" — language that suggests a barely restrained rejection of any state medicine. Behind the Conservative

Party there are always supporters who would prefer the State to lock away the mentally ill and throw away the keys.

Public confidence in the policy of running down and eventually closing Britain's long-stay hospitals and substituting instead care in the community is becoming increasingly fragile. Despite its honest denials, the Government is widely perceived to see community care as a money-saving exercise — a means of closing and selling off long-stay hospitals while providing care on the cheap in the community. The re-emergence on the streets of highly disturbed individuals visibly ill-cared for and incapable of enjoying a decent life not only offends the public's sensibilities, but also its sense of justice.

The message is beginning to come through — even from charities such as the NSF — that while the mentally ill may not be best cared for in hospitals, they are better cared for there than in the absence of facilities outside. The demand to return the mentally ill back to the bins "out of sight, and out of mind" could grow. Such a development would itself be a tragedy. The policy of making care in the community available is the right one. It is the execution which is proving weak. The running-down of mental hospitals is clearly happening more quickly than the provision of psychiatric support facilities in the community.

The problem is twofold. It is not just what to do with discharged long-stay patients. It is also about the standard of services for those who would have gone into long-stay hospitals but are now in some cases refused admission to keep the run-down on target. Parents and families too often receive little or no support. And the mess that has been made of the plans for regional secure units means that many psychiatric patients are ending up in prison not hospitals.

What therefore is to be done? The first thing is a clear admission from the Government that care in the community is not a cheap option, but one that will cost more. The idea, after all, is not just to shift the location of care, but to improve it. Mental illness services are chronically underfunded. Although in recent years there have been marked improvements in mental illness spending and staffing, the resources needed to provide decent community care are almost certainly larger than the cost of running the old mental hospitals. They may not be very much larger. What evidence there is, in an area where comparisons are hard and figures unreliable, is that the less dependent mentally-ill patients may well be cheaper to care for in the community, but that heavily dependent chronically-ill patients are appreciably more expensive.

The second is that bridging finance must be provided to ease the transition from hospital to community care. Here imagination as well as hard cash is needed. Despite the fact that the policy of closing mental hospitals is almost a quarter of a century old, not one of the large old hospitals has actually shut down. The harsh economics of running down a mental hospital is that cutting the number of patients by a half cuts the cost of keeping the place open only marginally, and that until it closes the often considerable sums of capital from sale of buildings and land are not realized.

As the hospitals run down health authorities are faced with trying to run two services at once. In addition, capital is crucial to community care. It is needed to provide the housing association places, day centres, hos-

tels, day hospitals, workshops and all the necessary elements of a proper community programme.

Some regional health authorities have set up bridging funds. But with health authority budgets under pressure the sums are insufficient. At least a three-pronged approach is needed. Some of the long-stay hospitals and their grounds, particularly if planning permission could be attached to them, are commercially attractive. Allowing health authorities to borrow against them, or to mortgage them against a firm closure date could in some cases release capital and revenue to develop community care now.

Regions which have not set up regional reserves need to be pressed by ministers through the annual review system to do so. But most importantly the government has to set up a substantial bridging fund of its own in the knowledge that much of it will be temporary extra expenditure. Once the closures take place, the savings will be realized. The money would be an investment in a future and better service, not an open-ended commitment to higher public expenditure.

With better central funding available the mechanism for developing community care programmes could be improved. Local authorities vary greatly in their willingness to take on more services for the mentally ill and some are wary of taking over health service spending for fear of the rate penalties such growth in services could eventually imply.

The channelling of bridging money through the joint consultative committees of local and health authorities plus local voluntary organizations which already exist could help ensure that it is spent only on well-developed plans where all three bodies agree the programme and objectives. In addition health authorities could be encouraged to contract with local authorities and voluntary organizations to provide services needed. Anomalies in the present funding system also need ironing out. Social security, for example, will pay the board and lodging costs of discharged mentally-ill patients in private accommodation and voluntary homes, but not in local authority homes or NHS-run residential facilities.

Anyone who has studied the problem of schizophrenia knows that the picture is not all gloom. A third of sufferers have a single attack, recover and never have a relapse. A further third go through a steady cycle of recovery and relapse. They may need many times to go through the so-called "revolving door" between institutions and the outside world. But as long as the facilities on each side of it are improved there is a chance that many of these will have the opportunity to live fulfilling lives for themselves and safer lives for their families. Only the final third of sufferers are condemned to permanent reliance on the health and social services.

The responsibility for alleviating schizophrenia has to fall on individuals, on families, on charities, on voluntary organizations, on local and on central authorities. It has to be shared more widely and more fairly than it has been up to now.

It ought not to be beyond the capabilities of British society to recognize the different needs of those who need to make only the one return trip through the revolving door, those who make many return trips and those for whom the journey is one-way for ever. Without such a determined recognition today's tragedy of mental illness will become tomorrow's public scandal.

The tragedy of schizophrenia: the neglected search for its

Cracking the mind's secret

Continuing *The Times's* investigation into schizophrenia, Marjorie Wallace reports on the latest brain breakthroughs

THE TIMES 20 JANUARY 1986

Nobody yet knows the cause of schizophrenia, the "forgotten illness" which affects one person in a hundred, fills nearly a quarter of all hospital beds, and costs the country hundreds of millions of pounds a year. But suddenly, after years of disappointment and false trails, scientists seem to be on the threshold of exciting discoveries.

"It's all becoming possible," says Dr Peter Williams, director of the Wellcome Trust. "Most people agree that with schizophrenia part of the brain is not working normally. But the brainbox is solid. You can't see what's happening in something surrounded by bone. In the last three years that problem has been solved and we can look into the brain and actually watch the chemicals in action."

Until these breakthroughs into the "black box", researchers had to wait until a patient died before dissecting his brain to find any abnormalities. The latest brain imaging techniques can show an immediate picture on a screen of what is happening in the brain, without harming the patient.

Brain watching is done by a number of new types of scanner similar in principle to the computerized X-ray scanner developed in Britain some years ago. The most important of them is the PET scanner which uses short-lived radioactivity inside the brain instead of X-rays. The radioactive substance is attached to a chemical and is injected into the patient.

Some of the chemical reaches the brain and as the radioactive atoms disintegrate, each one produces two bullet-like bursts of radiation that move off in exactly opposite directions. The apparatus times each pair of "bullets", and the computer works out to within a few millimetres what part of the brain they have come from.

The whole technology is extraordinarily complicated and costly. A PET scanner costs more than £2m. Because the radioactive substances used, such as fluorine-18 and carbon-11, decay to half their strength in minutes, they must be made and incorporated into the brain chemical only minutes before they are injected. They are made by being bombarded with atomic particles in a cyclotron, a kind of atom smasher.

When the computer has calculated where the radioactive atoms were when they disintegrated, it produces a map of the brain

showing where the injected substance ended up.

Over the past 10 years, many scientists have concluded that schizophrenia has something to do with a malfunction in the transmission of messages from one brain cell to another by a substance called dopamine. The idea came from the discovery that the neuroleptic drugs, discovered in the 1950s to control the acute symptoms of schizophrenia, blocked the transmission of messages by occupying the "receptor" normally used by the dopamine. It seemed as though the schizophrenic brain simply had too many dopamine receptors and benefitted when some were blocked off.

In various hospitals and laboratories, doctors were building up banks of frozen or pickled schizophrenic and normal brains to try to observe differences between them. In Britain, Dr Tim Crow and his colleagues made a large collection of brains at the Clinical Research Centre, Northwick Park hospital, near Harrow. Some physical differences were found.

6 We can now look inside the brain

In a third of the schizophrenic brains, mainly from people with chronic symptoms, there was enlarging of the ventricles—chambers filled with cerebrospinal fluid. He also found a thinning of cells in the parahippocampal gyrus and related structures in the temporal lobe, which suggested that cells had been destroyed or had failed to develop at some stage in the schizophrenic patient's life. But it was not clear whether this was due to the disease or the drugs the patients had taken, nor whether the destruction of cells was due to inflammation caused by a virus. Finding the cause of these changes could, according to Dr Crow, "alter our view of schizophrenia".

Apart from physical examination, parts of the brain were analyzed to find out the density of dopamine receptors. The schizophrenic brains contained more than the normal ones, so the theory looked promising.

As the analytical technique improved, different receptors of the brain could be analyzed separately for dopamine. Dr Gavin Reynolds, working at the Brain Tissue Bank at Adden-

brooke's hospital, Cambridge, made an extraordinary discovery. He found that in schizophrenics only, the left side of the brain, especially in a part known as the amygdala, contains more dopamine itself than does the corresponding part on the right.

"Already with these crude techniques we know there are abnormalities in the brains of some people with schizophrenia", says Professor John Wing, the acknowledged authority on schizophrenia in Britain. "The hottest bet is that there is something wrong with the dopamine system."

The new scanners seem to provide the answer. At present, they are mainly confirming in the living brain what has been discovered in dead ones.

Similarly, the PET scanner seems to be confirming for live schizophrenic brains the dopamine distribution in dead ones. Most of the work has been done in Sweden, France, the US and Japan. Britain currently has only one PET scanner, at Hammersmith hospital, which has not been working for nearly a year.

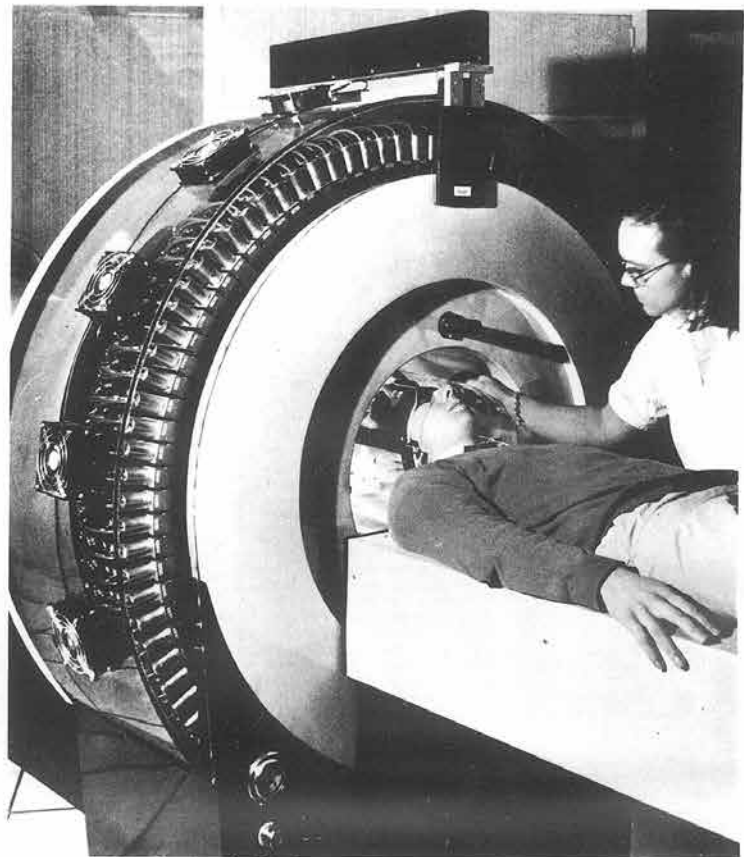
What are the implications of this research? If the dopamine theory can be confirmed, it may be possible to develop new drugs which will treat specific parts of the brain affected by schizophrenia. This could prevent the unpleasant side-effects of present-day neuroleptics.

"It's hard to imagine it, but if you could find a drug that worked on one side of the brain only, it might be very valuable in treating schizophrenia", says Dr Angus MacKay, chief superintendent at Argyll and Bute hospital. He does not rule out even more futuristic possibilities such as the use of discrete surgery if the exact spot in the left hemisphere associated with hallucinations, delusions and madness is located.

The dopamine theory points not only to a potential cure through better, more specific drugs but also towards a possible cause. "I think there are several kinds of schizophrenia with different causes", says Dr John Wing. "Damage to the brain before, during or after birth, or a virus infection, may be the origin of the trouble. Or in some families the disease may be hereditary."

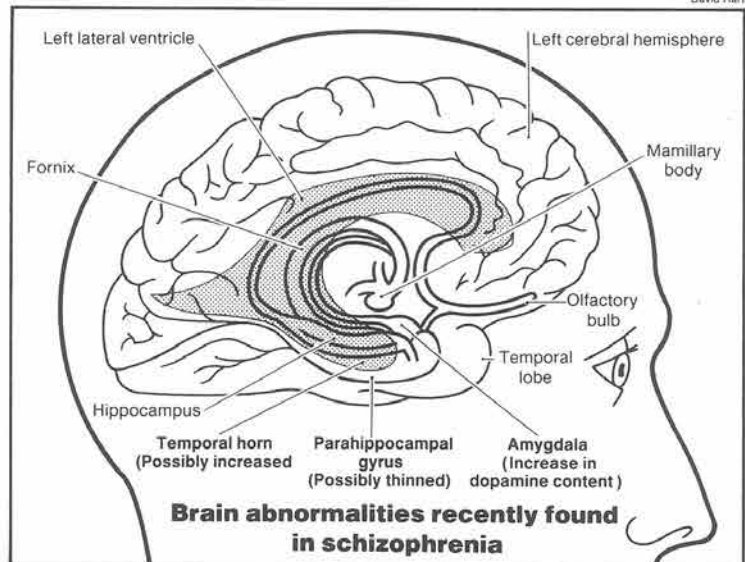
Drs Robin Murray and Adrienne Reveley, of the Institute of Psychiatry, suggest there are two basic types of schizophrenia: the inherited kind in which the ventricles of the brain are not enlarged, and the environmental type in which they are. There are also combinations of the two in different proportions.

They claim there are different degrees of genetic predisposition, as in di-



New images: the PET scanner which maps the disturbed brain

David Hart



abetes and heart disease. Where it is strong, the illness starts of its own accord. Where it is weak, some environmental "insult" is needed to trigger it, such as stress over exams, work and family relationships.

Laboratories all over the world are starting the search for the human gene or genes responsible for hereditary schizophrenia. The first step is to find a family with a history of schizophrenia from whom blood samples can be taken. Using the techniques of molecular biology, the researchers would separate the com-

plete range of genetic material contained in their blood cells. If schizophrenia involves only a single gene then, as for cystic fibrosis and Huntington's Chorea, the chance of identifying it is quite high.

If it could be identified, inherited forms of schizophrenia could, like Down's syndrome, be avoided by analyzing fluid from the womb during the first few weeks after conception, and if faulty genetic material is found, pregnancy can be terminated.

Perhaps the most cheering and unpublished new discovery comes from Dr

Tim Crow. In a study of 150 patients who have had their first schizophrenic breakdown, he found that the likelihood of having a further attack appears to increase the longer the delay before the person receives treatment with neuroleptic drugs.

In other words, people who are diagnosed and treated quickly are less likely to have a relapse. The neuroleptic drugs appear not only to master or control symptoms of the disease, but to stop the deterioration which makes the lives of schizophrenics so tragic.

cause and cure crests

“The Department of Psychiatry had three established chairs, an administrator, a neuro-physiological laboratory and its own animal house. Today there is one established chair, no administrator, no laboratory, no animal house”

The Clinical Research Unit at Northwick Park hospital on Harrow Hill was the great hope of the 1960s. The psychiatric unit provides Britain's major contribution to schizophrenia.

I went there last week and saw the “brain-bank” where 80 brains, some normal, some from schizophrenia sufferers, provided some of the first clues about what had gone wrong. We had to wear masks and gowns to protect us from the viruses the brains may contain.

Dr Frank Owen, the senior scientist, pulled out a blood-covered brain, handling it like a joint from Sainsbury's. “Some of our brains are rather nasty,” he said in explanation of the biohazard warnings everywhere. “They can still transmit a rare but fatal form of dementia even years after they have been frozen.”

The laboratory has a budget of about £400,000 out of the £500,000 the MRC spends nationally on schizophrenia. (In America, the National Institute of Mental Health has an annual budget of \$23m for extra-mural studies in schizophrenia alone.) The brain-bank studies are the biggest project in the laboratory, costing more than £200,000. But the whole scale of the research is minuscule compared with the MRC's total budget of £124m. Even this modest budget is under threat.

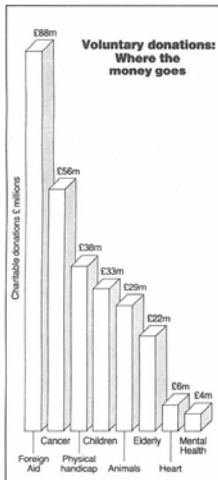
A committee set up to review the future of the Clinical Research Centre will make recommendations at the end of the month. “We know there is a decrease planned in the total MRC funding, so we assume the centre will be cut to at least that level,” says Dr Tim Crow, head of the psychiatry division. “We'll just have to make the best of whatever they recommend. It's foolish to cut state funding for this research when the burden of care is falling on the state itself. It makes sense to put money into schizophrenia research, even on purely economic grounds.”

The MRC appears to be moving away from specific research on schizophrenia, and is putting stronger emphasis on research into the neurobiology of normal brains.

In the universities, too, there are heavy cut-backs. In the past year four chairs of psychiatry have been merged or abolished and another one is to go shortly. “In 1974,” says Professor Robert Kendell, “the Department of Psychiatry had three established chairs, an administrator, its own neuro-physiological laboratory and its own animal house. Today there is one established chair, no administrator, no laboratory, no animal house. Morale has never been lower.”

Pressure is being put on hospitals, too. At Runwell in Essex the bank of pickled brains, the first and largest in Britain, has been under threat of closure but has had a temporary reprieve.

The problem, however, is not simply one of money. One charity, the Wellcome Trust, with £28 million a year to spend from the profits of Burroughs Wellcome, is eager to put money into worthwhile research projects on mental illness. At present the trust spends just £300,000 to £400,000 a year on mental health research. But it has recently given £4 million to Glasgow University for work on senile dementia, and is advertising £3 million over 10 years for any group wanting to set up a PET scanner project.



“The hope is that by brain imaging with a scanner we will be able to see,” says Dr Peter Williams, the trustees' director. “Research is in depression, partly because of the cuts, and partly because work on mental illness is not fashionable. You can't attract people to something difficult when they can go in for easier research. The number of people and the number of ideas they produce is limited.”

The Medical Research Council has the same problem. The quality of applications is not good enough. “We lack the culture for encouraging research,” says Tim Crow. “There are few people going into clinical research, and even fewer in this area. There is a lack of enthusiasm.”

There is one courageous voice in the depressing chorus. Gwyneth Hemmings, founder of the Schizophrenia Association of Great Britain, has recently raised more than £40,000 for research into projects such as the possible link of diet and schizophrenia.

Dr Robin Murray, Dean of the Institute of Psychiatry and noted for his success in obtaining support for his research, sums up the sad story: “At no time have the prospects for schizophrenia research been brighter; at no time have the prospects for the researchers been so dim.”

Counting the cost of a daughter's death

How one family will have to pay to get at the facts of their schizophrenic daughter's death; Marjorie Wallace reports

THE TIMES
23 DECEMBER 1985

Ruth and James Joly today face legal fees of £3,000 to discover how their mentally ill daughter came to die on a hospital outing to Brighton. The daughter, Angela Joly, aged 41, a patient at St Mary Abbots hospital in west London walked into rough seas from Brighton beach and, in spite of a rescue attempt, drowned.

The hospital telephoned the woman's parents at their home in St George's Square, Pimlico, London, and told them of her death, but gave no further information. To find out what happened they had to instruct lawyers to represent them at the inquest and to cross-examine witnesses.

The inquest was held at Brighton coroner's court on November 26. Mr Edward Grace, the coroner, was told that a party of 29 patients and 11 staff from the hospital went on the annual coach outing to Brighton last August. On arrival the party split up. The staff went shopping in the Lanes, and the patients wandered around the streets or strolled on the beach unsupervised.

A consultant psychiatrist at St Mary Abbots told the inquest that Miss Joly was greatly distressed and had made a number of suicide attempts in the past.

A statement read by the woman to staff and patients at the hospital the day before the outing was read to the inquest. It described “her violently self-destructive anxiety” and Mr Norman Perrin, a fellow patient, told the court how Angela Joly had been greatly distressed on the journey and had threatened to get off the coach to return to the hospital. He had told another patient and member of the staff who had tried to comfort her.

At the end of the seven-hour hearing the jury returned a verdict of misadventure.

In a letter to the hospital, Mr Grace questioned whether she would have been permitted to go on the outing and whether the patient should have been allowed to do whatever she wished without supervision.

He made recommendations to prevent similar accidents: that patients should be assessed before such an outing, and that



Angela Joly, who had a long history of mental illness

staff should always be available and aware of patients' activities.

For Mr Joly, a retired naval officer and his wife, the lack of information or concern from the hospital about their daughter's illness summed up 20 years of frustration. They say they had been told repeatedly by social workers that there was nothing wrong with her beyond being over-dependent on her family, spoiled and finding

difficulties with relationships.

Mr Joly says: “Because she was an adult, she was deemed by the doctors and social workers to be able to regulate safely her own affairs and to be better off forced to do her own thing and not to be confined.”

She had a long history of mental illness, at one time diagnosed as “schizo-affective”. She had been a gifted child who grew into a beautiful and popu-

lar young woman. At the age of 18 she won a county award to Oxford University, but within two weeks of arriving there she had broken down.

Doctors told the parents very little about what was wrong with their daughter, and she improved sufficiently to get a degree at Bristol University. She obtained a series of responsible jobs but was unable to keep any of them.

The loss of a job often triggered acute anxiety and on several occasions she was admitted to hospital. Four times she attempted suicide. After another attempt at Christmas 1984 she was left to live on her own in a flat but could make appointments to see hospital social workers. At the inquest Mrs Joly told the coroner: “They were always telling her she had to stand on her own feet and become more independent from me. Every time she came back from a visit to the social worker, she seemed worse than before.”

By May this year Angela Joly was so depressed her general practitioner advised that St Mary Abbots accepted her as an in-patient. This they did reluctantly. Her medication, a fortnightly injection of Mocatec, a neuroleptic drug that controls the more acute symptoms of schizophrenia, was reduced. She became brighter, but more disturbed, claiming the television set was talking to her.

One July evening, about four weeks before the fatal outing, she attempted to hang herself. Shortly before her death she told her parents that the hospital was ordering her discharge.

Judith Bryant, chief nursing officer for the Riverside Health Authority responsible for St Mary Abbots, said last week: “The nature of the outing and its purpose was to test the independence of patients in fairly controlled circumstances and attempt to assess their ability to cope.”

“As a result of the coroner's inquest we will be looking carefully at the circumstances surrounding Angela Joly's death and at the recommendations made by the coroner. The relationship between adult psychiatric patients and the hospital has always been a difficult issue. The parents are not as close to the situation as they would like to be.”

Mr and Mrs Joly are prevented from bringing a case for medical negligence because it would cost at least £25,000 and the waiting list for such cases is three or more years. “We do not want to blame or ruin individual careers, but it would have lessened our bitterness had the hospital admitted their failures,” Mrs Joly said. “Surely the present unsatisfactory attitude to both parents and their supporting families will change so that common sense and compassion will prevail.”

ANGELA'S LEGACY

Miss Joly left a number of poems including this one entitled “Angela's Legacy”

*If you were here
I would hold you
And let you find
tranquility in my arms,
Peace beyond understanding,
Repose beyond my body.
But with my heart
And broken mind
My dreams I give to you.*

THE TIMES 21 JANUARY 1986

Coroners criticized over mental patients

By Marjorie Wallace
The deaths of schizophrenics who commit suicide are being recorded as accidental deaths or misadventure because of coroners' reluctance to return suicide verdicts, Dr Martin Weller, a leading psychiatrist said yesterday.

Evidence that coroners are reluctant to return suicide verdicts has been collected by *The Times* and Central Television, whose *Zero Options*, the first of

two programmes on schizophrenia, is broadcast tonight. The programme claims that one in 10 schizophrenia sufferers will commit suicide.

Dr Weller, a consultant psychiatrist to Friern Barnet, has carried out research showing that the suicide rate is 17 times higher in schizophrenics than in the whole population and even higher among those just discharged from hospital.

“There is a reluctance by

coroners to record a verdict of suicide,” he said. “I had one schizophrenic patient who jumped from a high building. His death was recorded as misadventure.”

Mr David Lyne, director of the North-West Fellowship for schizophrenia said: “Last year 18 of the schizophrenia sufferers from the 100 or so I know committed suicide.”

According to the programme, James Andrews, aged 23, threw himself

under a train in Hertfordshire after two previous attempts to take his own life, but the verdict of accidental death was recorded.

The programme also examines the shortfall, and failure, of community care to meet the needs of schizophrenics. “Community care is an empty shell,” Dr Michael Tarsh, consultant psychiatrist at Prestwich hospital, Manchester, said yesterday.

Can the government relieve the tragic plight of homeless schizo

The minister acts

Ros Drinkwater

In a frank interview with **Marjorie Wallace** and **Nicholas Timmins**, Sir Norman Fowler, then Secretary of State for Social Services, replied to the articles on schizophrenia in *The Times* with clear commitments to tackle the disease which fills a quarter of all NHS beds. Present government policy is to discharge patients from hospital and to develop community care. Is it working?

THE TIMES 17 FEBRUARY 1986

The Times: Do you accept that schizophrenia is a medical illness for which the sufferer has the right to treatment under the National Health Service?

Fowler: I think that schizophrenia is a medical illness and patients should have whatever treatment the doctors think necessary. The change over the last 20 years is that psychiatrists try to avoid lengthy inpatient care. It is not just the policy to close long-stay mental hospitals. It is rather a positive policy to provide care tailored to the individual's need.

The Times: There are some groups who are sufficiently disillusioned with the way it is working that they believe the policy should be halted. There is evidence from relatives, doctors and the police that hospitals are refusing to admit patients who need treatment. We have also heard from psychiatrists who say they are being forced to discharge patients into the streets.

Fowler: I think that is to exaggerate the position that we have in the country generally. It is clearly not the case that all problems have been resolved but the picture is one of the community care developing, not deteriorating.

The Times: Do you accept that services must be provided in the community for individual patients before they are discharged from hospital?

Fowler: Yes. A doctor should not discharge a patient before satisfying himself that there is a satisfactory pattern of living awaiting him. It has to be said that most patients are not statutorily detained and some will discharge themselves.

The Times: But the Society of Clinical Psychiatrists, for example, said they were turning the mentally ill out "into the streets, lodging

houses, gutters and prisons". Our experience in talking to psychiatrists confirms their concern. Is it right that this should be happening?

Fowler: No. No one would want it to happen. One of the most important things we must do is evaluate objectively what is taking place and I have decided we will devote some extra resources — between £100,000 and £200,000 — to research projects to test the effectiveness of community care and make the kind of evaluation you want. No individual should be discharged into a situation where services do not exist.

The Times: Do you accept that care in the community will be a more expensive option?

Fowler: I do not think for one moment that it is a cheap option. The aim is not to save money, but to use it responsibly. We spend just over £1 billion a year on mental illness and we must use those resources to best effect. But I think that in some circumstances there is no question that it will be more expensive and I wouldn't want to run away from that. In a sense that follows from the sort of priority that we give to this area.

The Times: Do you accept that some patients will require continuing long-term care, effectively "asylum" for the rest of their lives?

Fowler: If you mean by that refuge and protection, that is unquestionably the case. It could be in hospital, it could be a house in a street. We will need in-patient accommodation for older long-stay patients who were admitted before modern medical methods were developed and who in many ways regard that hospital as their home. Then you have continuing in-patient care for the small number who are, if you like, the new long-stay patients



Norman Fowler: 'No one should be discharged into a situation where services do not exist'

who, despite advances in treatment, cannot be supported in the community. Plans are needed for suitable accommodation such as hospital hostels for this group. We do accept that.

The Times: Some psychiatrists are saying however that their region's plans do not provide for that sort of asylum. Will you be saying to them that they should make that provision?

Fowler: Yes. We have the ability to do that.

The Times: Do you accept that large-scale savings from running down a mental illness hospital effectively occur only when the hospital closes?

Fowler: I think that is almost certainly right, although obviously there are useful savings as wards close.

The Times: Do you therefore accept that health authorities are having effectively to run two services at once — the old hospitals and the developing community service?

Fowler: Yes. We are in a period of transition from one to the other. That is why we have again urged regional health authorities

to develop some form of bridging funding to carry services over this expensive time. I will be talking to the 14 regional chairmen about that over our next two meetings.

The Times: Does that mean you are considering some additional central government money for bridging finance?

Fowler: I will want to talk about how effective their bridging finance has been, what the problems are and see if there is some way that we can help them.

The Times: Financially?

Fowler: Some of them might say there is a case for central financial help. I cannot promise that but I think it is sensible we should talk about it for the reason that in a period of transition you do have the costs of running two services rather than one.

The Times: Can you provide an assurance that when mental hospitals are closed the funds will be used specifically for the care of the mentally ill?

Fowler: Yes. We say that unless there are exceptional reasons the receipts should be earmarked in that way.

The Times: If health authorities do not do that, have you got any sanctions?

Fowler: Certainly. Ultimately I have the power of direction. It is not a power which is used a great deal.

The Times: Do you have any plans to end the use of unregistered and too often sordid bed and breakfast accommodation for discharged schizophrenic patients?

Fowler: I would very much like to initiate a simple checking process because in many cases accommodation, not just for the mentally ill, is being financed through the social security system. I find it in principle offensive that we should be spending money for accommodation which does not come up to anyone's idea of a good standard and anything I can do to help I will seek to do. I cannot easily ask my own social security department's local officers because they are under a great deal of pressure. I wish I had the officers to check on that accommodation but I don't think I have. Local authorities are the obvious people to take an interest in that area.

The Times: But local

authorities are under no statutory obligation.

Fowler: Clearly they would say that this is an extra duty, so I don't have any neat answer.

The Times: Do you recognize the fear of many involved with the mentally ill that the proposed guidelines to the Mental Health Act (1983) will make it more difficult for people to get the treatment they require?

Fowler: There is no question of seeking to remove a doctor's discretion so that it prevents people receiving the treatment they need. The real issue is one of compulsion. There are important questions regarding our civil liberties and the purpose of mental health law is to strike a balance between the rights of the individual and the community at large.

The Times: Do you accept that the nature of schizophrenia itself prevents people being able to make decisions regarding their need for treatment?

Fowler: Some of them may not be able to do that some of the time.

The Times: Are you sat-

shrenics?

The articles on schizophrenia generated hundreds of pertinent and moving letters, only a fraction of which we had room to print. Below is a selection of letters that appeared in *The Times* following Marjorie Wallace's first articles

LETTERS TO THE EDITOR

Caring for schizophrenics: everyone's concern

24 December 1985
From Dr Richard Smith
Sir, By some poignant stroke of fate I read your excellent editorial on schizophrenia (December 19) while sitting on the Tube with a man who told me he had just been discharged after spending 15 years in a mental hospital. He probably was not a chronic schizophrenic, although he had the abnormal facial and body movements of restlessness that are characteristic side-effects of major tranquilizers, the drugs used to control schizophrenia; more his problem seemed that he had a very low intelligence. But whatever his diagnosis, his plight was that of many who have been hastily expelled from long-term care. Dishevelled, dirty, and cold, he approached me on the platform and told me that he hadn't eaten for three days - since he was discharged. He then kept repeating the same

themes: he had no money, nowhere to sleep, and no job; nobody had spoken to him for three days; and he wanted to go home - to Liverpool. As your editorial makes clear, this is not an unusual story. But only a minority of *Times* readers, I suspect, know such stories first-hand and why I write is to describe my reaction and that of the people around me. I wasn't scared because I encountered many such people when I practised as a doctor, but I was wary of him. I didn't believe everything that he told me and, although I gave him some money, I stopped short of giving him the £6 he said he needed to get home on the bus to Liverpool. I could have afforded it but something stopped me; partly I thought he might be conning me; partly I was worried he would attach himself to me; but mostly I felt that it wasn't my problem.

Concern on schizophrenia recognized

21 December 1985
From the Chairman of the Mental Health Act Commission
Sir, None can fail to be moved by your three-part series (December 16-18) on the plight of schizophrenics and their families, in hospital or in the community. We at the Mental Health Act Commission are acutely aware, too, not least of the problem of isolation. Teams from among our 90 members visit mental hospitals and social service departments every week. We were set up by Parliament from many professions, to look

after the interests of detained patients in the special and other hospitals. Our concern, too, is what happens to them when they leave. All patients who so wish are talked to, the issues they raise discussed with staff and management, and complaints pursued. Everything possible is done to raise or maintain standards so that the best practices prevail. A vast range of points arises. Examples can be found in the commission's recent report, including one complaint about a schizophrenic patient and her family. Yours faithfully,
COLVILLE, Chairman, Mental Health Act Commission, Room 22, Hepburn House, Marsham Street, SW1.

Government action on schizophrenics

23 December 1985
From the Joint Parliamentary Under Secretary of State, Department of Health and Social Security
Sir, Your leader of yesterday (December 19) dealt with a subject which is important to me. No one who has spent a day with the National Schizophrenia Fellowship can for a moment forget schizophrenia and the unhappiness it brings to the sufferers, their families and those who care for them. You ask for a "clear admission from the Government that care in the community is not a cheap option, but one that will cost more." Health authority plans provide for rising expenditure over the next 10 years. These plans show that authorities have heeded the Government's urging to shift expenditure towards priority services. At the same time spending by local authorities (which have a much smaller share in mental illness expenditure) continues to rise - by 42 per cent over the last five years. I welcome your firm declara-

tion that "the policy of making care in the community available is the right one". But you appear to have some misconceptions about DHSS policy. The Government has not urged health authorities to discharge long-stay patients. Indeed, statistics confirm that the number discharged in 1983 was considerably lower than the number discharged in 1973. As our policy paper says: "Patients who would be better off outside hospital should have a planned discharge to suitable care even if no closure is foreseen; patients who are better off in in-patient care should continue to receive such care, by a transfer if necessary, even if a closure is planned." The fall over the last 30 years in in-patient care has now reached a point where some hospitals are uneconomic to run. We have, therefore, urged health authorities to plan comprehensive alternative services, including the transfer of long-stay patients where appropriate. As your article indicates, the closure of a minority of hospitals are crucial to putting right the present anomaly under which 90 per cent of the patients are in the community while 90 per cent of the resources are in the hospitals.

Second, the number of community psychiatric nurses providing a lifeline to the chronic patient at home is growing fast. Some 18 months ago, as part of our wider "helping the community to care" initiative, we financed work in three health districts specifically aimed at the chronic schizophrenic. These were designed to improve communication within a district. A key point was the involvement of the carers, as trusted allies of the professionals. Your article has only confirmed my acute concern that the heroic efforts of carers should be recognized. The DHSS is doing all it can to see that professionals give them more help and move in effectively if and when the carers can no longer cope. I welcome the moves which the Royal College of Psychiatrists has already made in this direction and I shall see that practical help to the carers is given the priority it deserves. Yours faithfully,
TRUMPINGTON, Department of Health and Social Security, Alexander Fleming House, Elephant and Castle, SE1.

Distressing side effects

27 December 1985
From Dorothy N. Thomson
Sir, I should like to say how much your major articles on schizophrenia are appreciated. I have been a sufferer for 10 years, I am possibly one of the lucky ones, having had only one relapse two years ago, when in consultation with my psychiatrist, it was tried to get me "off" medication. However, it would appear that I shall have to take medication for the rest of my life. This in itself is not too much of an inconvenience. The worrying thing is the prospect of increasing side-effects as I grow older. The term for this is *tardive dyskinesia*, to which a programme was devoted recently on television. Unfortunately, although Depixol, Medecate or similar drugs render one "sensible", in the process one becomes aware of these side-effects - trembling, restlessness or spasmodic mouth movements. They can be as distressing as the illness itself. Your article points out quite rightly that a person in the full throes of an attack often does not realize his own condition. Awareness of these side-effects results in a feeling of freakishness and loss of confidence. DOROTHY N. THOMSON, Agnew Terrace, Edinburgh

Serious misgivings

27 December 1985
From Ian Gordon
Sir, As the father of a young man who committed suicide while on weekend leave from the psychiatric wing of the local hospital, where he was being treated for schizophrenia, I have grave misgivings about the state of psychiatric medicine. When we had questioned the extremely high dosage of drugs being prescribed for my son, we were told bluntly that the dosage was necessary to prevent his killing himself. However, neither the fact that my son had twice attempted suicide while at hospital, nor the fact that he had been deeply depressed the previous week, caused the medical staff any compunction about allowing him home that ill-fated weekend. One of the factors in support of the policy of returning patients who are disturbed mentally to community care is the bland assurance of the psychiatric profession that patients' behaviour can now be controlled by drugs. In my experience of the way my son's condition deteriorated while under drug therapy, confidence in the skills of modern psychiatric medicine is patently misplaced. Yours faithfully,
IAN GORDON, Beach Road, Hartford, Northwich, Cheshire

ified with the way the section procedures are working?

Fowler: It appears that the present procedure for statutory admissions is going well. There have been some complaints, usually from general practitioners, about social workers, about that. But I think things should improve.

The Times: Thousands of relatives of schizophrenics are providing support for them at great cost and stress to themselves. What plans are there to assist them?

Fowler: The National Schizophrenia Fellowship has said that what relatives most want is sensible planning and information in relation to discharge and aftercare. They put that ahead of financial help.

Two years ago we financed three districts, Hackney, Southampton and Salford on projects to create co-ordinated aftercare. That means there will be plenty of consultation with relatives before patients are discharged with information about the illness and practical advice on how to respond to different situations. The programme is drawn up in consultation with the patient and the family, and micro-computers are used to sound the alarm if perhaps through a change of staff, there was a danger of somebody falling out of the system. When the development stage is over we would like to look at them and adopt one of the packages.

The Times: It is ironic that Southampton was where we found some of the worst cases of poor aftercare.

Fowler: I think it is fair to say this is going to take a year or two to reach fruition, but I don't think what you have just said is incompatible with what we are trying to achieve.

The Times: Going back to all the evidence of the desperate situation some families find themselves in. Have you any other ways you can help for example widowed mothers who are living in terror of being attacked physically by very strong sons who are not in hospital because of the policy of community care? Have you got any comfort for them?

Fowler: I have no blanket solution for that. We all have problems like that from our own constituencies. What does matter is that there is the maximum amount of local involvement and local knowledge by all the agencies and people understanding what the position is. The general policy must be that people will in many cases be discharged to their families and that is right and proper.

There are real difficulties about people who are violent, but most schizophrenic patients have no more recourse to violence than you or I.

6 January 1986
From Richard Forrest, Havelock Rise, Luton, Bedfordshire

Your series of articles on schizophrenia (*Spectrum*, Dec 16, 17, 18) came at a bad time of the year for me. My wife suffered from this appalling illness. She killed herself two years ago on December 17. Your account of the horrors suffered by the families of victims of the disease left me amazed at the capacity for suffering these people must have. In my case, the period between the onset of the breakdown and my wife's suicide was less than three months. When I remember what I endured during that brief period, and consider that some human beings may have to endure the same for years on end, I feel a sense both of shame and helplessness. The shame comes from the feeling that, though I want to be able to help, I cannot face the thought of confronting in someone else that depth of desolation and despair I arrived at during this period. The helplessness comes from my own attempts to help my wife come to terms with her illness. I fear that nothing I did or could have done had any effect other than to drive her deeper into her emotional trap. In the space of a few weeks, I

watched a warm, highly intelligent, deeply religious young woman whom I loved more than anyone else change to a cynical, manipulative, brutal and unfeeling stranger. I could cope with her hearing voices, getting messages from the radio and television and being watched day and night by people using special cameras. But to see a stranger looking at me out of my wife's eyes, and realizing that I could not know if her protestations that she loved me were true or a sham designed to manipulate me was almost beyond enduring. Had I not had the responsibility of care for my young children, I believe that I would by now have taken my life, as she did. The onset of my wife's illness was very sudden, but I was able to obtain psychiatric help fairly quickly. Schizophrenia was diagnosed only in the week before she died. Looking back at the events, I can see a reluctance on the part of the medical staff either to talk to me of the possibility of schizophrenia, or apparently to face it themselves. I can well understand this reluctance. In my wife's case there would have been no way of distinguishing between a cure,

and a convincing imitation of normal behaviour. Certainly she could pass herself off as completely normal. In particular she convinced several of her friends that any peculiarities in her behaviour were due to my bad treatment of her. One actually accused me of driving her to suicide. Following a half hour interview with my wife, one psychiatrist suggested that I needed psychiatric treatment rather than her, as my behaviour was causing her problems. As I was being told this, my wife made her first suicide attempt. It was following this event that schizophrenia was first mentioned as a possibility. This uncertainty must be a great problem for doctors. In the case of schizophrenia, it seems impossible to judge success. This cannot help, either in maintaining a commitment to study the disease, or in treating it. After the immediate shock of my wife's death, one of my strongest reactions was a feeling of relief. My normal process of grieving has been complicated by the emotional hammering I suffered during her illness, and my memories of her are distorted by the images of the

creature she became. Feeling guilt about this sense of relief has been part of my problem. Your articles have helped me by illustrating that my worst fears of what could have happened had she not died were justified, and that the effect this would have had on the children was potentially far worse than that of losing their mother. More than anything else, I wish she could have been cured, and that I could be with her again as she was before her illness. I believe this is the only way in which the wounds inflicted on me by her illness can fully be cured. This is now impossible in this life. 6 January 1986
From Anthony Clare, Professor of Psychological Medicine, St Bartholomew's Hospital Medical College

In fact, the 1983 Act, like its predecessor, the Mental Health Act 1959, makes it plain that a mentally ill patient may be detained if it is deemed necessary for the health or safety of the schizophrenic patient concerned. However, as the series showed, relatives of the mentally ill find themselves increasingly unable to obtain help from psychiatrists until patients are so disordered and disorganized as to be gravely at risk to themselves and others. While there are several admirable controls built into the 1983 Act to ensure that patients are not detained wrongly and have access to an independent appeals tribunal there are no equivalent controls to ensure that when they are suffering deterioration they are actually detained and treated. The Mental Health Act Commission is understandably vigilant in seeing that I and my professional colleagues do not overstep our legal powers but appears indifferent to the possibility that we will increasingly refrain from using them, preferring instead to indulge in of defensive medicine. Indeed, the draft Code of Practice being prepared by the Commission may well make the compulsory admission and treatment of such patients even more difficult.

TALKBACK

A survey conducted in 10 countries indicates that schizophren

Schizophrenia: the root of

There are 17 million people in the world suffering from schizophrenia. A new study absolves families from most of the blame and suggests it is an illness, not a social condition.

Marjorie Wallace reports.

THE TIMES 3 MARCH 1986

A worldwide epidemiological study of schizophrenia carried out by the World Health Organization over the last eight years will throw new light on the disease and may help to reveal its cause.

It also has important implications for the way we cope with victims and the role played by the families.

Dr Assen Jablensky, a Bulgarian epidemiologist and the Senior Medical Officer in WHO's Department of Mental Health last week told *The Times* the results of this study, due to be published in June. The survey, the first to quantify new cases, was started in 1977. It was carried out in 12 research centres in 10 countries — Colombia, Czechoslovakia, Denmark, India, Ireland, Japan, Nigeria, the United Kingdom, the United States and the Soviet Union.

The researchers went to great lengths to identify all new schizophrenics in the different centres, not only through hospitals and doctors, out-patient and community centres, but also through the help of faith healers, shrines, sooth-sayers and other non-traditional sources. The total number of patients was 1,352.

Using a computer, the WHO doctors employed standard methods of diagnosis. They took details of case histories and followed up each patient over one year, two years and, in some cases, five years.

The extraordinary result was that in all 10 countries the incidence of new cases of schizophrenia was virtually identical, about one per cent, of whom half were serious cases. Because social and economic con-

ditions vary so widely between the different countries, the study showed that schizophrenia is not brought on by particular socio-economic conditions.

Similarly, because family relationships and culture vary so greatly, it is very unlikely that families cause their children's schizophrenia. "The study should relieve any feelings of guilt," Dr Jablensky says. "Families cannot be blamed and those who take comfort from the evidence that schizophrenia has a biological basis should be further reassured." He believes the study demolishes the concept of the schizophrenogenic mother, who causes schizophrenia by a mixture of over-protection and expectations of independence.

‘The findings should relieve guilty feelings’

But while culture and family do not affect the incidence of schizophrenia, they can dramatically alter its progress. "Where the schizophrenic can be contained within a large family network where the atmosphere is more supportive and less demanding, his chances of recovery are much higher," says Jablensky. In developing countries like Nigeria or India many patients suffer a single schizophrenic episode followed by a complete recovery. In Nigeria 58 per cent of those followed up were of this type. In India, it was 51 per cent. In Denmark, with smaller families, only six per cent recovered completely.

This interpretation of the results supports research by Dr Julian Leff and Dr Christine Vaughan of the Maudsley hospital, London, indicating that families which are critical and make demands on the sufferer (high expressed emotion families) are three times as likely to trigger a relapse than are calmer families. This was also confirmed in the WHO survey in both India and Denmark.

In this and previous surveys, the pattern of poorer prognosis extended throughout the developed countries where up to half the patients followed up became chronic schizophrenics.



Paul Leith



Reassurance: Dr Jablensky

There are also geographic differences in symptoms. In poor countries the onset of the illness generally is sudden, the patient has no previous signs, he comes from a stable family background and develops strong florid symptoms, such as hallucinations. His chances of remission after the first episode are good. By contrast, in richer countries, the patient is often socially withdrawn and lives alone or in an unstable family. There are more negative symptoms, such as apathy, lack of motivation and bleaching of emotion, and the prognosis is worse.

Despite widely-differing cultures, patients all over the

world described their symptoms with an eerie similarity. Hallucinatory voices discussed them in the third person, commenting on every action and thought. They felt their thoughts had been taken over or "read" by some alien agency, and broadcast at large. Patients in countries as different as Nigeria and Denmark described their feelings with almost the same words and phrases. This seems to point to a common biochemical cause.

"I was surprised by what we found", Dr Jablensky says. "I expected there would be significant differences in the incidence of the disease in different countries as

happens in diabetes and heart disease. The only other conditions that show the same uniform distribution are epilepsy and mental retardation." Clearly, there is a genetic component underlying schizophrenia.

He believes that there is probably a variety of causes and that schizophrenia is the name for many syndromes. He thinks an episode may be activated in a similar way to an epileptic seizure. Schizophrenia could be the consequence of a developmental defect in the brain during the first few years of life. "We should look into birth injuries and early development," he says.

This area is being re-

searched both by Dr Tom MacNeill in Sweden and by a study of twins by Drs Robin Murray and Adrienne Revely at the Institute of Psychiatry, London. Twins suffer more birth traumas than do single children, and Dr Revely has found they also commonly have enlarged brain ventricles (chambers filled with cerebro-spinal fluid). Many people with schizophrenia have significantly enlarged ventricles.

"If we could find out what is going wrong in the maturation of the nervous system", Jablensky says, "it would help us understand why in later years a person develops schizophrenia."

enias has a biological basis the problem

AN INTERNATIONAL SCANDAL

Nearly 30 years ago American psychoanalysts challenged the traditional view that schizophrenia was an illness that needed medical care. Steeped in the Freudian concept that all behaviour has its root in infancy, they believed schizophrenia was caused by early conflicts in relationships, particularly with the mother. Victims should therefore be treated by psychoanalysis rather than by drugs.

The idea quickly took hold in analysis-mad America and in the 1960s Thomas Szasz took it to its extreme, claiming that all mental illness was a myth created by psychiatrists. Soon others were jumping on the bandwagon. Sociologists Erving Goffman and Thomas Scheff declared that people became schizophrenic not only because of their parents or psychiatrists, but also through social pressures to conform. The sufferer was not mad, but a victim of society and should not be locked away in hospital.

Their exposure of conditions in these hospitals alerted the libertarians who raised the banner for "patients' rights"

and campaigned for changes in the laws which allowed people to be hospitalized against their will. Those discharged should be looked after in the community.

These ideas spread through Europe during the 1960s and 1970s, becoming entangled with flower-power, intellectual socialism, student protests and left-wing resistance groups like the Baader-Meinhof gang.

As a result of these "reforms", thousands of destitute mental patients are crowding the streets of the major cities of Europe and America and their plight is becoming an international scandal. Now the pendulum is beginning to swing back. "The anti-psychiatry movements contain the seeds of their own destruction," says Professor John Wing of the Institute of Psychiatry in London. "A lot of what they say is based on fantasy. They want to make all mentally ill people normal. But in some cases the patient is too ill and it becomes obvious in the end that it is inhumane to put such pressure on him."

The Times checked how the picture was changing in a number of countries.

UNITED STATES



The swing has been most dramatic in the United States where, even five or 10 years ago, psychiatrists interested in biomedical research found it very difficult to get professorships. Today, it is important to have this bias. Six months ago the new director of the National Institutes of Mental Health announced research on schizophrenia was to be a priority.

The scientific community now accepts that schizophrenia is an illness and not caused by psycho-social factor," says Dr Fuller Torrey, consultant psychiatrist and well-known critic of the civil liberties approach to schizophrenia.

"There has been a universal realization that the running down and closure of mental hospitals in America has been a disaster," says Torrey. "The numbers of mentally ill sleeping rough or in shelters has escalated and it is now estimated that 37 per cent of the men and half the women (two-thirds in Washington DC) who are homeless suffer from mental illness. Last year a mental hospital in Texas was taking weekly loads of patients, driving them 200 miles to a bus station in St Austin, Houston, and discharging them there with either 'Family' or 'Salvation Army' written on their discharge notes." Dr Llewellyn Bigelow, consultant psychiatrist at St Elizabeth's hospital in Washington confirms the "disillusion" with reforms of the 1960s and '70s: "It's a hot political issue between civil liberties lawyers and pressure groups of families, supported by some congressmen. There are groups actively lobbying to reverse the State laws to make it easier for people to be committed to hospital."

WEST GERMANY



In the 1960s the movement reached West Germany and became associated with various left-wing and libertarian causes. One of the most vehement was Dr Wolfgang Huber, of Heidelberg University, who attempted to put treatment into the hands of the patients. He became involved with the Baader-Meinhof gang and was imprisoned for possessing ammunition.

Another group of young psychoanalysts, who called themselves the Mannheim Circle, also attempted to break

away from the medical model. Through their efforts, psychiatry was redefined to exclude neurologists.

But none of them was able to change the mental health laws, or have a hospital closure policy adopted. "Community care is difficult to fund in Germany," says Dr Steen Mangan of the London School of Economics. "Unlike Britain, German health services are funded by insurance companies. Hospitals lose money when there are empty beds."

UNITED KINGDOM



In the UK, a plan was put forward in 1961 to close many of the old-fashioned asylums. But it was nearly three years before the civil liberties people took up the Government's plan and the analyst Ronald Laing became a cult figure with his theory that families create madness. In the mid 1960s, Larry Gostin, an American lawyer, came to this country and, working with MIND (National Association for Mental Health) lobbied for hospitals to be closed and championed the cause of patients detained compulsorily. The movement has been successful in forcing changes to the Mental Health Act (1983) which make it more difficult to treat a patient who is so ill he refuses help.

ITALY



The anti-psychiatry movement had its major triumph in Italy. "There was a tremendous ideological movement with student protests, worker protests and then the government saw it as a lovely way of cutting down on bills. As in other countries it was a unique fusion of left- and right-wing motives," says Professor Kathleen Jones of York University, who has studied Italian mental health reform. In 1978 communist-inspired legislation prevented new patients from being admitted. The asylums faced eventual closure and many of their patients were decanted into the community. The result was crowds of *abandonnati*, as they became known, on roadsides and railway stations.

The situation became so embarrassing and serious that in 1992 the policy was reversed and a number of asylums were reopened.

SWEDEN



Despite similar pressures from civil liberties groups, the Swedish government has adopted a cautious approach. "Politicians are slowing down the closure of mental hospitals and a report lobbying for reforms in mental health laws has just been rejected," says Dr Frits-Axel Wiesel from the Karolinska Institute. "We are learning the lessons of America and Italy. We do not like big institutions but they are better than being discharged with no alternatives in the community."

EASTERN BLOC



The anti-psychiatry movement never reached the Soviet Union or the Eastern European countries, which remained faithful to a rigid medical model. Since the Soviet Union regarded its social structure as correct and beyond criticism, the idea that mental illness was due to social conditions was unacceptable. There was no policy to close the hospitals, although the major centres were developing community care through psychiatric dispensaries and sheltered employment. Many patients used to end up in long-term secondary hospitals, which were not part of the health service. It is unclear what the position is since the breakup of the Soviet Union.

FRANCE



Psycho-analysis has always been very popular in France and anti-psychiatry ideas were eagerly taken up, especially by the intellectual left and Communist Party. As in Germany, the definition of psychiatry was changed to exclude the neurologists. France has a programme of hospital closures and a regional structure of catchment areas, which is known as "sectorization". But this scheme relies on a person having an address and patients can easily fall through the net. "There are armies of discharged patients who travel from one hospital to another, being to be admitted for short periods," one of the French experts told *The Times*.



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A CIVILIZED DUTY

Late last year *The Times* ran a series of articles on the topic of schizophrenia. Under the general title of "The Forgotten Illness", they set out to remove the many misconceptions about the disease, to describe its scale and tragic effects, and to expose the anguish and neglect which both sufferers and their families have experienced largely because of ignorance about it. There was an extraordinary response to the articles in the form of letters to *The Times*, and the series' author, Miss Marjorie Wallace, was named Campaigning Journalist of the Year in the British Press Awards. Their most recent (and most important) effect however, was the announcement this week of a national schizophrenia appeal to be launched in March 1987.

There are a number of reasons why an appeal is needed. The first is that the effect of newspaper articles, however compelling, is inevitably transient. Without the more insistent pressure of an organised charity, people tend to forget both the scientific facts of the disease and the gaps in public provision for which ignorance is partly responsible.

In the case of schizophrenia, the myth of the Jekyll-and-Hyde "split personality" soon reassesses itself. In fact, the illness is a disorder of the brain, probably bio-chemical in origin, which distorts the way a person thinks and views the world. It comes in cycles, but there is no way of knowing when, why or how the bouts of mental anguish recur. A third of people have one breakdown and recover completely. A third struggle between periods of madness and sanity. A final third never fully recover. They go on to lead wasted lives and their minds and personalities decay.

In many cases the worst symptoms of the disease can be controlled by neuroleptic drugs such as largactil. But these

have unpleasant side effects — involuntary shaking, for example — and more research would probably find more effective drugs and the right doses. New techniques such as scanners, which allow doctors to see for the first time how these drugs act on the brain, are available. But the money to buy and operate them is lacking. Schizophrenia has been an unfashionable illness, and research into its cause and cure underfunded.

The problem has been made worse by well-meaning government policy. Community care is a good idea, and nobody wants schizophrenics locked away in the old asylums, but by running down the hospitals before the planned network of hostels, workshops and day-centres are built, we have created a new population of destitute, homeless people who are abandoned without treatment and end up in poor lodgings, in prison or under the arches. It is estimated that 60 per cent of the homeless are discharged mental patients, mostly schizophrenic. More than anyone, they need sheltered employment.

Existing charities, however, are mainly self-help groups with small resources and little outside support. The new appeal — Schizophrenia: A National Emergency — is more ambitious. It aims to raise money for research into the cause, treatment and eventual cure of schizophrenia, and to put pressure on government and local authorities to stop the dumping of patients into poor lodgings or even onto the street. It also hopes to establish after-care schemes.

There is no more important duty upon a civilized community than its care of the mentally ill, for they cannot help themselves. With the public interest aroused by Miss Wallace's articles and the establishment of the Sane appeal, that duty may begin to be met.



HRH Prince Turki al-Faisal (right) with SANE's Chief Executive, Marjorie Wallace and Professor Colin Blakemore at Oxford University discussing the new Prince of Wales International Research Centre which is to be built in the city.

First International Research Centre

The charity Sane is planning the world's first international centre for schizophrenia research, following this week's launch of a £6 million appeal by HRH The Prince of Wales.

Through an introduction by Nicholas Egon, husband of Matti Egon, the Greek shipowner, King Fahad, Custodian of the Two Holy Mosques of Saudi Arabia, has pledged £1.75 million on the day of the launch, subject to SANE being able to match the sum from other sources. The Centre will be named

after HRH The Prince of Wales (who became Patron of SANE in 1989) and will be located at a university where there is a strong tradition of neuroscience: contenders were Edinburgh, London, Manchester and Oxford.

Marjorie Wallace, Chief Executive of SANE, said: "We have already had discussions with leading researchers in the field and I have had the pleasure of introducing HH Prince Turki to world famous neuroscientists, such as Professor Colin Blakemore, at a dinner at Magdalen

College. It will be quite a challenge to match the generous gift from Saudi Arabia. Fortunately we have the personal commitment from HRH The Prince of Wales, and that will help.

The Centre will act as a focus for research into the cause or causes of schizophrenia and depression; it will act as a catalyst to other researchers, nationally and internationally; and a forum for collaboration and exchange of knowledge about these neglected illnesses.

Cutting corners on mental health care facilities has grave implications Heading for a break

It is government policy to extend and improve mental health care in Britain. Yet this week the internationally-renowned Maudsley hospital faces cuts that would severely restrict its unique and important ability to treat the mentally ill. On the eve of a critical meeting of the health authority, Marjorie Wallace reports from inside the hospital.

THE SUNDAY TIMES 11 MAY 1986

It is six o'clock in the evening. Most of the patients have gone home, leaving the waiting area littered with cigarette ends and paper cups. In an ordinary out-patients' department the doors would now be locked, but here at the Maudsley hospital on Denmark Hill, South London, the emergency clinic remains open throughout the night to serve anyone whose misery or inner turmoil has become intolerable.

This is a casualty department for the mind: the only one in the country which remains open 24 hours a day and accepts mentally distressed people, wherever they come from, without an appointment or even a doctor's letter. Whatever a person's background, it is often their only hope of being seen immediately.

There are no stretchers, drips, or queues of anxious relatives in this clinic, but the atmosphere is no less tense. There is something eerie and disturbing about an invisible crisis which could so easily be one's own. "It's just as upsetting as dealing with a gross accident," says Mary, a student nurse.

The stillness is shattered as two police officers escort a very dishevelled woman through the swing doors. "I done murder and arson," she protests. "I gotta be punished. Please let me go to prison." She rolls back her sleeve to show rivulets of dried blood.

Dorothy, who is in her 30s, is well known to the police and to the clinic. She has been brought here four times in the last week, mostly for directing the traffic and helping old ladies to the other side of roads they do not want to cross. Today she has been stopping children outside their school to show them her "stigmata", the deep razor scratches she inflicts on herself.

"She is not schizophrenic. She is very, very unhappy," says Dr Andrew Johns, the senior registrar. "Her husband died a year or so ago and she does not

understand why he stays underground. She is convinced he is hungry and must take him food. She wants him to come and live in his coffin in the house."

This time, the staff feel she may do herself real harm if she is sent away and, because she will not come into the hospital voluntarily, they prepare to detain her for up to 28 days under section two of the Mental Health Act.

For an hour or so the clinic is deserted. There is an uneasy feeling. Two nights ago, at about this



Eric Byers: balancing the books

time, a man arrived, threatening to kill the doctor with a kitchen knife. As in a general hospital, the Maudsley has an emergency team on call which can react within minutes. The interview rooms have alarm buzzers under the desks.

"I was terrified," says Dr Simon Wesseley, the duty doctor that night. He had every reason to be afraid. People arrive with all kinds of weapons. "There is one young man," says Jo Brand, the senior nurse, "who carries a holdall in which he keeps an arsenal of weapons — a machete, an air rifle, throwing knives, even a pickaxe."

Tonight's drama is more subdued, but heart-breaking. Lorraine, a sad young West Indian woman, arrives with her five-year-old child, Jamie, who, at first,

simply seems lively, but within minutes is rushing around, hurling himself against the furniture. Jamie is laughing, swearing, scratching and spitting while his mother makes limp attempts to control him. "He must see a doctor. It's an emergency," she tells Mavis Greene. The nurse explains that the clinic does not see children and is about to send her away.

"You see it's about child murders," Lorraine explains. "There is this tramp who follows him back from the nursery. I wrote to the police... You see, he's been putting chalk marks at my door, Xs and XT for extremist... sometimes he uses yellow chalk — that's when he wears yellow trousers. Sometimes it's green chalk and green trousers. I didn't notice they matched at first... my son's beginning to look like him. He's getting into his mind and making him say rude things." She is painfully deluded and explains that the tramp is telling Jamie to kill her.

Nurse Greene calls Dr Sue Behr who spends half an hour assessing the mother. The story is familiar. Lorraine had a severe paranoid schizophrenic breakdown after the birth of Jamie and has been in and out of hospital for the past five years.

It is government policy that people suffering from schizophrenia and other mental illness should, wherever possible, live in the community. So last summer when Lorraine was discharged from hospital she went to live in a council maisonette, alone, with her son. She appears to have no close family and has not seen a doctor since her discharge. The social services have been "keeping an eye on her".

The doctor decides both Lorraine and the child are at risk and that she must be admitted to hospital at once, even if it is necessary to "section" her. Jamie is by now running riot and Lorraine, exhausted by her delusions, finally relents to becoming a voluntary patient and signs an order which will put her son in the care of temporary foster parents. Just after midnight she leaves Jamie, now a pathetic little figure asleep on a chair. A social worker gently lifts him in his arms to take him to his new home.

Of the 6,000 patients seen by the emergency clinic every year, more than half simply walk in without being referred by doctors or other agencies. Many have suffered panic attacks. "We see lots of people who feel as though they are choking, that they are going to die," says staff nurse Frankie Rechter.

Some patients literally have gone out of their minds through grief or emotional crisis. A couple of nights earlier, there had been pandemonium when a sophisticated professional



Emergency clinic

Family in distress: five-year-old Jamie and his mother

couple visited the clinic. The young woman was shouting hysterically, threatening to kill herself if her boyfriend ended their relationship. The girl was suffering from what is termed acute reaction to stress. "It's a terrible problem to decide whether to section an otherwise well person," says Dr Simon Fleminger, "but she had cut her wrists on a previous occasion and could have tried something again." However, section two of the Mental Health Act requires the agreement of a second doctor and social worker and, as often happens, neither would agree to the doctor's request to admit her. The rowing couple eventually left.

The imaginative, caring approach of the Maudsley's emergency clinic, acknowledged throughout the country by those concerned with mental health, is now in jeopardy. At a meeting of the special health authority which runs the hospital, proposals will be made for economies which would severely restrict its work.

For a saving of a mere £30,000 a year, the night service would be reduced by moving the clinic to the

back of the hospital where it would be staffed by a porter and one nurse. Moreover, the clinic would only accept patients from the Camberwell district; people from outside the area, who at present account for two-thirds of the clinic's caseload, would have to join the accident victims across the road in the King's College Hospital which already has the most over-crowded casualty department in the country. "It's like a battlefield. They don't even have an interviewing room," says Dr Andrew Johns. "It would mean that far fewer patients would be helped."

And that is precisely what is intended by the man who is proposing the cuts — the recently-appointed general manager, Eric Byers. He is a former product director for an American textile company who was brought in six months ago under the recommendations of the Griffiths Report which advocated the employment of managers with a background in industry. "Too many patients are admitted to the hospital through the clinic," says Byers. "It attracts custom. If we provide the service for other hospitals, they will never develop their own."

Byers manages the 500-bed Maudsley and its sister hospital, the 200-bed Bethlem Royal in Beckenham, Kent, and acts as chief executive of the special health authority. It did not take him long to discover that the hospital was overspending by £8,000 a week as well as having debts of £420,000. The package of cuts he is presenting at tomorrow's meeting would save at least £400,000 a year.

"We have to balance the books", he says. "I did not create the crisis, I walked into it."

Even so, his approach has enraged the hospital's staff. They say that the cuts he advocates would undermine some of the most valuable areas of care built up at the Maudsley since the war. As well as restricting the work of the emergency clinic, he has proposed:

- Closing the alcohol addiction ward, which the consultant says would make out-patient care and research impossible;
- Closing the children's neuro-surgery ward for eight weeks a year and running it for only five days a week, which doctors say is unworkable;

Applications for the community kdown

Michael Ward



visiting the "casualty department for the mind"

● Relocating either disturbed children or mentally-handicapped children to the Bethlem Royal's adolescent unit, thereby mixing children such as sexually-abused girls with psychotic teenagers, which the doctors warn would destroy the work they now do with the children's families;

● Closing Ward 2, which acts as a mini day centre and provides beds for severe cases from the local community.

Although Byers accepts that some of his proposed cuts could undermine the national importance of the Maudsley, he says that by restricting services to people within the catchment area he is only carrying out official thinking. "We should be following the government's plans for medicine to be less bed-centred and based more in the community," he says. "There is a philosophy of care behind the cuts."

His caring philosophy is not appreciated by the staff, in particular the doctors, who have organized protest meetings and plan a rally tomorrow. They claim that without the flexibility of being able to take people in for special treatment at a

moment's notice, out-patients will be neglected and lives could be lost.

This is critical in services like Ward 2 and the alcohol unit. "It is the only specialized alcohol addiction centre in London," says Professor Griffith Edwards, who has built it up over 20 years. "People with drinking problems are 80 times more likely to kill themselves," he says. "If you get blind drunk when depressed, before you know it, you are dead."

His staff treat thousands of people as out-patients but there is a 10-bed unit where specially trained nurses look after those whose drink problem has more serious underlying mental illness. Without this fall-back, Edwards claims, he would have to close down the unit and abandon research.

He resists the proposal that his patients should join the drug addicts at the Bethlem Royal. "Nobody will visit them when they are with the 'junkies' among the rhododendrons," says Edwards. "And the addicts there don't want to associate with a 'load of old lusers', as they call them."

Like other parts of the

hospital, the ward for the alcohol unit is spartan and grubby. Its stained grey linoleum reflects the dismal skies outside. A girl plays billiards in one room while the others sit in rows around the day room, smoking and staring. A few lie under candlewick bedspreads on primitive dormitory beds. But the atmosphere among the staff and patients is relaxed and informal. The "uniform" of the hospital is jeans and trainers; there are no white coats.

The senior registrar for Ward 2, Dr Mossen Naguib, is equally worried about what would happen to his patients. "We take people from the community who do not fit anywhere else. If the ward is closed, I have patients who are too ill to go to a hostel or return home. They will probably have to wander the streets." He also fears the Maudsley would have to stop providing second opinions for patients from other hospitals where all other treatments have failed.

"The Maudsley has always been the place the rest of the country turns to as the ultimate authority," says Dr Naguib. "Even modest cuts will destroy its unique role."

Thousands of mentally ill people throughout Britain are being abandoned in squalid lodging houses or even simply decanted on to the streets. They have been "returned to the community" from mental hospitals as part of a policy called "community care" — a liberal-minded reform of the Sixties which has become a national scandal in the Eighties.

The policy was started partly in response to liberal pressure and partly to save money. Compared to £200 a week in hospital, the cost of social security payments for the keep of the mentally ill in the community can be as low as £70 a week.

The move towards community care — reinforced by the government in the Seventies — worked well at first, largely because the least ill patients were the ones being released.

But now the Department of Health and Social Security (DHSS) is returning progressively less suitable people to the community. In the last 27 years, the mental hospital population has been cut by half — more than 70,000 have gone and a further 20,000 are expected to be released as the large mental hospitals are run down. Yet few local communities either want them or have the resources to look after them.

The *Sunday Times* has examined the plight of such people in several towns across Britain. This article is centred on Southampton because it has a relatively good reputation for providing a proper after-care service for those patients in releases. We have plenty of evidence of similar cases up and down the country.

As recommended by the DHSS a department of psychiatry has been attached to the general hospital in the centre of the town. Besides an out-patients' department, it has 65 beds to provide short-term treatment for acute cases. In addition voluntary housing groups and other charities have been given financial help and a day centre has been opened.

Yet, even in Southampton all is not well for the mentally ill.

I found Nick Rayment, a 37-year-old schizophrenic, lying pale and shaking in a Southampton bed-and-breakfast house. It was nine o'clock on a bleak autumn morning. He had been lying in his bed for two days, nursing bottles of Valium and penicillin, listening to "the voices" in his head, too afraid to move out. "I'm dying," he said. "I need help."

His landlady, Dot Stanton, said: "We get lots like him. He should be in hospital. I only do B & B. He just turned up a few days ago and I took him in."

I got Rayment downstairs and into a car. He covered like an animal, then lunged aggressively at me. "I want to stab my

Bedsit despair of the mental hospital outcasts

Marjorie Wallace
examines the
failure of
community care to
cope with the
mentally sick

THE SUNDAY TIMES
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cigarette in your eyes. My voices are telling me," he said.

We headed for the department of psychiatry at Southampton general hospital, which had been treating him as an outpatient. Two days earlier, he had tried to get himself admitted. He was refused and when he caused a fuss, was ejected by the police.

A consultant at the department, Dr Philip Milln, was hostile when he learned we were from a newspaper.

"What do you want us to do?" he asked. "Put him in a chemical strait-jacket and leave him in the ward of a mental hospital? A chronic schizophrenic upsets the delicate work we are doing with 'treatable' cases here."

Later that day, after I had left, Rayment was again discharged and went back to the same B & B.

It is a cruel dilemma. Dee Heaps, an adviser to the National Schizophrenia Fellowship, says: "The hospitals haven't got the revenue to run the beds and are using their 'clinical judgement' as an excuse to turn patients away."

Ron Scott, at the St James's Night Shelter, talked about Terry — "a pitiful man" with the mentality of a 12-year-old. "The hospital wouldn't have him because he was not 'treatable'. He got badly beaten up on the streets. In the end, we had to advise him to go shoplifting so that he could get into a police station. It was the only thing to do."

Bernard Flew, 41, was even less fortunate. "I had an epileptic fit yesterday," he told me when we met. "I get no warning. Nobody got a doctor." Three weeks later, I learned that he had been found dead by his B&B room-mate, another ex-psychiatric patient.

About a third of Southampton's mentally ill, it is estimated, are living in private lodgings.

Dave Flegg, 37, runs two B & B places inhabited mainly by homeless families, ex-offenders and the mentally ill. Dave's Guest House is near the town centre and the Solent Hotel is in the "red light" district. Both places were strongly criticized in a report to the council earlier this year.

Flegg has 29 rooms in the guest house, 19 in the hotel, yielding £35 to £40 per week per "guest". At the time of the report to the council, there were frequently five to a room.

But Flegg — short fair-haired and theatrical — said: "I provide the best value-for-money accommodation in Southampton. I'm doing a public service."

At the Solent Hotel, he led me from one sordid room to the next until we reached the cramped TV room. There he addressed the handful of dishevelled people with a vaudeville flourish. "You like it here with Dave, don't you, ladies and gentlemen? Don't you get a good breakfast with Dave?"

Running B & Bs for social security residents is an expanding business, with an assured income from the state and almost no controls. A DHSS spokesman in Southampton said: "It is not our responsibility to examine the places. We hand out the money."

Robert Brown runs one such place in Southampton. He has 10 ex-patients in five bleak rooms. There are two showers but no bath. Brown, 66, hands out the medication, including powerful tranquilizers, to those guests who cannot manage on their own. For each guest, the DHSS pays him £70 a week, a total of £700. Recently, Brown was convicted of buggery and fined £200 at Winchester crown court.

The scandal of the mentally sick is a national one. I found similar patients in London, Oxford, Birmingham, Swansea and Newcastle.

Despite the big drop in the mental hospital population, only about 10 per cent of last year's £857 million health budget was spent on outpatients and day care. The community care policy throws the onus on to the local authorities — but they are not legally obliged to act.

From their total social service budgets, only 1.1 per cent overall is spent on community help for the mentally ill. One-quarter of local councils provide no day care whatever for the mentally ill; one-fifth offer no council residential accommodation.

The scale of the problem is enormous. MIND and other agencies believe that one in eight women and one in two men go through mental hospitals at least once in their lives. What happens to them when they come out depends — and will depend increasingly in future — on community care.

John Wilder, director of the Psychiatric Rehabilitation Association, says: "People who need to be in hospital are walking the streets, often dangerous to themselves and others. They are the new vagrants."

Roger Scruton



Nick Rayment, lying in bed listening to his "voices" and afraid to move out

In the United States as in Britain, pressure is growin

The inner terrorist, the invented life

Last night 100 influential people met in the presence of the Prince of Wales to be told about plans for a major new appeal, SANE — Schizophrenia: A National Emergency. The disease affects one per cent of the population; one of these people is John Hinckley, who five years ago shot and wounded President Reagan. Marjorie Wallace talked to his parents about the shock of discovering their son's hidden fantasies, and about their campaign to help the mentally ill

THE TIMES 1 JULY 1986

On March 30, 1981 the telephone rang in the Hinckleys' mountain home in Evergreen, Colorado, not far from Denver. Jack Hinckley, a caring Christian, was at the office preparing for a trip to help the poor in Guatemala. His wife answered the phone. "Mrs Hinckley," said a voice, "this is *The Washington Post*. Do you know that your son John has been identified as the man who shot the President?"

That bald statement transformed the Hinckleys' lives. Jack was a successful businessman with his own oil exploration company. His wife, Jo Ann, had made a pleasant home. There were friendly neighbours, a local church and a good golf course. Their three children had grown up. Scott, the eldest was working in his father's company. Diane was married. Only their younger son, John, gave them any cause for concern.

John was a gentle, aimless fellow who in the seven years since he had left school had been unable to complete any college course or hold down even the most menial job. He was a shy young man who, even in his 20s was approaching 15 stone.

The disappointing pattern of his life continued, with Jack and Jo Ann alternately nagging and consoling him. They would receive calls from cities all over America, saying his money had run out, he had nowhere to live, and needed to be rescued. He would describe in great detail his relationship with his girl friend Lynn Collins, an actress in Los Angeles.

"We tried everything," says Jack. "I thought Jo Ann was too tender. Maybe I was too tough. I would say 'all he needs is a good kick in the pants.'"

Anxious, but not unduly

alarmed, they sought help from a psychiatrist who originally told them John was spoilt and lazy and depended too much on his home. Three months before the tragedy the family aged to draw up a plan whereby John would find a job by the end of February and his own apartment by the end of March.

The psychiatrist insisted his calls for help should be ignored. "There I was saying to my son, 'You're on your own,'" says Jack "while he was losing his battle against the terrors of insanity. We just didn't know."

But the plan for his independence proved the final threat for the lonely young man. For the first three weeks in March, he booked himself into the Golden Hours, a cheap motel a few miles from his home. There he planned the act by which he would communicate with the world. Eight days before the shooting, he told Jo Ann he wanted to find work in Los Angeles. She drove him to the airport, pleased that at last the "plan" was working. That was the last time she saw him free.

The next time, he was brought by prison guards. "What do you say the first time you see your son after he has done the unthinkable?" recalls Jack Hinckley. "Why did you shoot the President, son?" Instead, "we told him we loved him," he says.

During the next weeks Jack and Jo Ann went through hours of interrogation at the Jefferson Hotel in Washington. Gradually the bizarre world their younger son had inhabited was revealed. Lynn Collins, the actress he had described so vividly, had never existed.

Everything was a fabrication: the writing courses that he had never taken; the

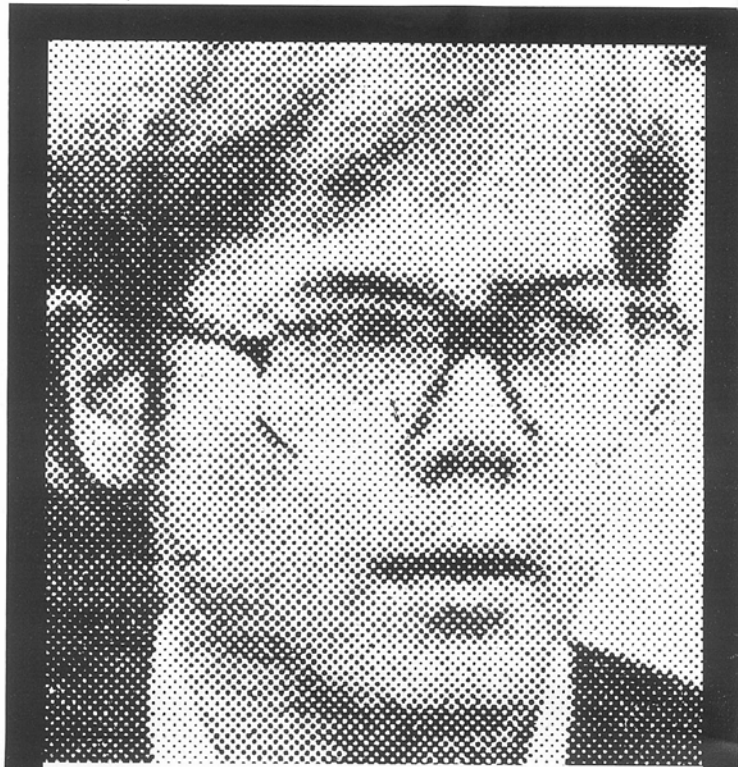
company he discussed so proudly; the close college friends who had barely heard of him; the glittering Christmas spent with film stars and music publishers in New York. In reality he had spent it alone in an unheated room on a deserted campus, paralysed by depression and self-loathing. The FBI showed the Hinckleys a snapshot John had taken of himself with a time-release camera, holding a gun to his head.

At home there were more chilling surprises. Jack and Jo Ann opened the cases in his bedroom, filled they believed with old college possessions. Lying on top of a pile of clothes was the empty pistol case and the cut-out target of a man, riddled with holes. And here were the poems, revealing his despair. "Perhaps the Elephant Man would understand my dilemma... it's all a matter of face-to-face communication... the Elephant Man and I would kill for someone to love."

John had also become fascinated by the character of Travis Bickle in the film *Taxi Driver*. The film became his reality. He collected guns as Bickle did. He stalked political figures as Bickle had done. And he



The attempt at President Reagan's life shook the world



(NY55-June 21)--INNOCENT-- John W. Hinckley Jr. was found innocent by reason of insanity Monday when a federal jury ruled he was not criminally responsible for his attempt to assassinate U.S. President Ronald Reagan. (AP Laserphoto)(ysk22010f1s)1982

John Hinckley, the schizophrenic who, in 1981, tried to assassinate President Reagan

was going to shoot people for the heroine, Jodie Foster's sake because that's what happened in the film.

It was not until just before John's trial, six months after the investigation began, that Jack and Jo Ann learned he was probably suffering from schizophrenia. "Like everyone else, we thought schizophrenia was like Jekyll and Hyde," says Jack. "Not the loss of self and the deep split with reality which we now realize lay behind his odd behaviour."

"If Jo Ann and I had known the early warning signs of mental illness, there would probably have been no shots fired. President Reagan would not have been shot. White House Press Secretary James Brady would not have suffered permanent brain injury."

John was found not guilty by reason of insanity and placed in the maximum

security wing of St Elizabeth's Hospital, Washington DC, one of the most old-fashioned asylums in the United States.

He is now 30, and living in the John Harvard Division, a relatively modern six-storey block, separate from the main buildings. He is in a ward with about 20 other men overlooking the hospital cemetery.

He is on medication and once in a fortnight the Hinckleys visit him for an hour's session of family therapy. "It has made a tremendous difference," says Jack. "We've been able to talk about the difficult things. We found it difficult to communicate, but now we have been forced to do so, we are very glad."

The American public was shocked by the not guilty verdict, and the Hinckleys were equally shocked by the lack of sympathy for a sick man. "Two years ago Jo Ann and I decided to start a public awareness campaign. After the tragedy of the trial, we had to see some good come out of it. 'Why don't you speak for the mentally ill?' a lot of people asked us. One fellow wrote to me saying, 'Hinckley, your name's already mud. You've nothing more to lose.' It was a bitter pill, but it made me think."

The Hinckleys received thousands of supportive letters from others with mental illness in their families. They decided to write a book, *Breaking Points* (published by Berkley Books in May) to help remove the cruel stigma of mental illness. Then they

went to Washington and founded the American Mental Health Fund. Jack sold his oil company to devote himself to the fund, which will educate the public and provide money for research.

The fund is managed by an eager young man, David George, who was legislative assistant to Senator Jeremiah Denton. Hinckley, George and their associates succeeded in persuading the Advertising Council, a body which makes advertising space available virtually free of charge to a small number of selected charities, to back the fund, which will get about £16 million worth of advertising in 22,000 different media for the expenditure of £230,000.

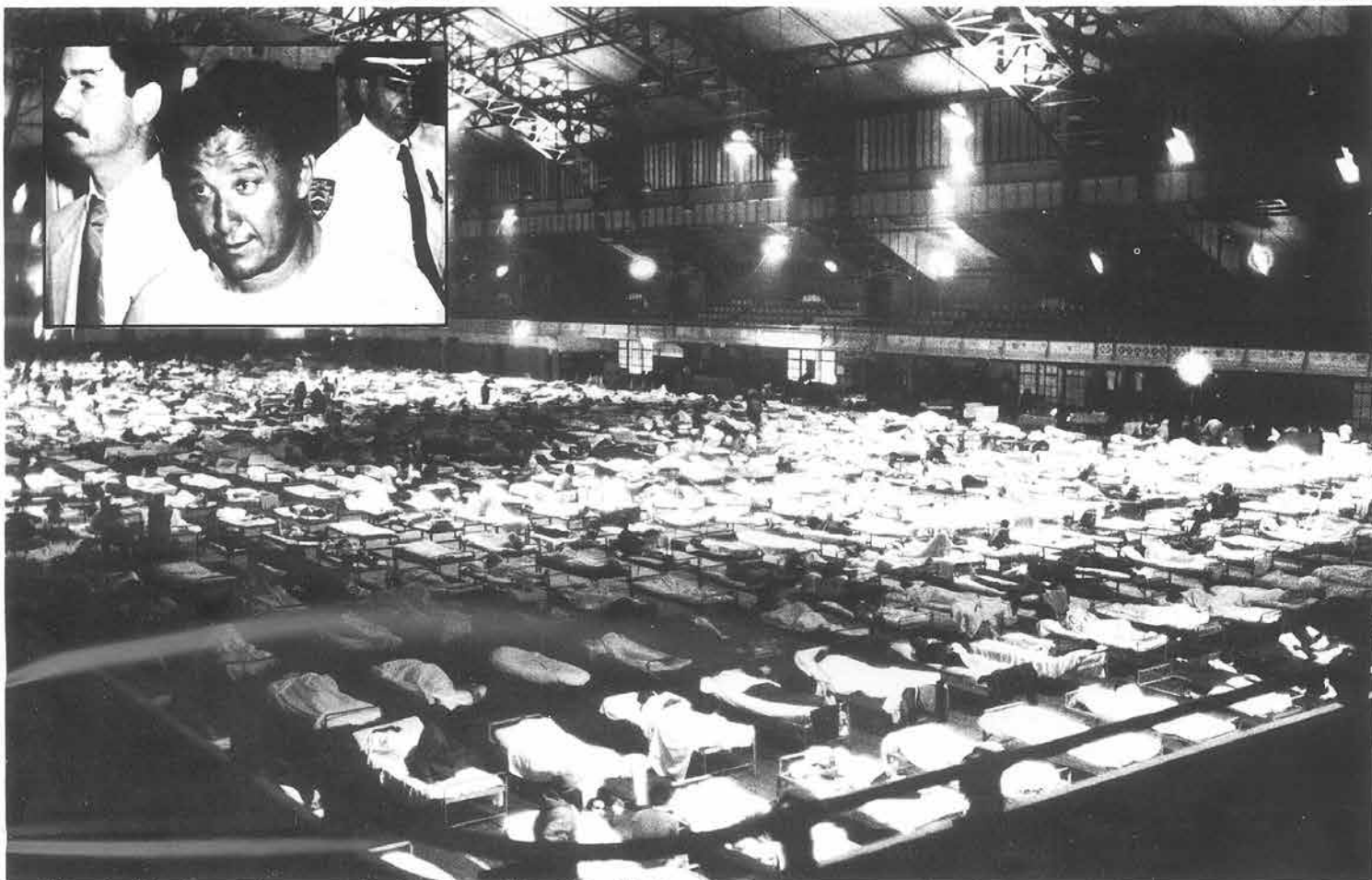
"A recent Gallup poll showed that 57 per cent of Americans think mental illness is a personal weakness," says George. "We want to change that. We want to make people aware that it exists, and make them believe it is an illness. We aim to raise a dollar for every person affected by mental illness in America. That will make \$30 million for research."

On July 17 the flood gates will open, and for the first time the American media will be full of information on mental illness. "The US is today preoccupied by the fear of terrorism from abroad," says Jack Hinckley. "My concern is with another form of terrorism — the inner terrorism that each year strikes an estimated 100,000 new schizophrenia victims."

g for more awareness of the plight of schizophrenics

Associated Press

Ruby Washington/NYT



Where death lies dormant: the cavernous Fort Washington shelter, from which Juan Gonzalez (inset) set out on a ferry ride to catastrophe. How many more like him?

The sword at America's bedside

Murder on the Staten Island ferry. Two dead. Just another American nightmare? Not really. Marjorie Wallace reveals how potential killers are being sent out onto the streets and into harm's way

THE TIMES 11 JULY 1986

The ferry from Manhattan to Staten Island was passing the newly-refurbished Statue of Liberty last Monday when panic broke out among the 500 passengers. Juan Gonzalez, a 43-year-old Cuban immigrant, was rushing round the decks brandishing a 24-inch pearl-handled sword. Within moments he killed a man and a woman and wounded nine other people.

He is one of the 7,500 homeless people, many of them mentally ill, who spend their nights in New York shelters. An even larger number, frightened

by the desperate conditions, prefer to sleep rough in the port authority bus station on 42nd Street.

Gonzalez chose as his bedroom the Fort Washington shelter, an enormous drill hall in Harlem, which he shared with 900 other down-and-outs. The hundreds of iron cots are arranged in neat rows, like a first-aid post after some great disaster. The dim lights are on all night. There is the continual noise of human torment — screams, moans and shouting to imaginary voices. Around the edge of this great raft of

beds, red-uniformed attendants stand ready to sort out the arguments and fights which break out occasionally.

The Thursday before the boat killings, Gonzalez had been the centre of a disturbance. Attendants called the police when he started screaming: "I'm going to kill. God told me to." The Presbyterian Hospital held him for 48 hours, recognized his symptoms as paranoid schizophrenia, and discharged him back on the street on Saturday night, suggesting he should seek out-patient treatment at Harlem Hospital. In New York, as in Britain, hospital policy is to discharge mentally-ill patients as quickly as possible. "It was a terrible mistake," admitted a psychiatrist at the Presbyterian Hospital.

On Monday, instead of visiting Harlem Hospital, Gonzalez who, like many others, was probably too ill to realize he needed treatment, took out his sword and bought a ticket to Staten Island. He is now in King's County Hospital, New York, undergoing a 30-day "evaluation".

The case is typical of thousands, except that very few schizophrenia sufferers are violent, merely sad. In the United States, as in Britain, pressure from well-meaning civil liberties campaigners has brought about the run-down or closure of mental hospitals before means of looking after the patients in the community have been provided. Some years ago there were 550,000 beds in

American mental hospitals to cater for two million schizophrenia sufferers. Now there are only 130,000.

Sick people are being abandoned on the streets. Their presence — hundreds of thousands of them, hungry, dirty, deluded — haunts New York and the other big American cities.

The scandal is so great that the mothers of this human flotsam are no longer willing to see their sons and daughters made victims of neglect. Their only choice is to keep their severely-ill grown-up son or daughter at home, receiving no help, or to lie awake at night thinking of their child sleeping in a mass night shelter or worse. They have now become so desperate that they are forming groups for political action. The National Alliance for the Mentally Ill has increased the membership of its 500 affiliates by 85 per cent in the past year.

"The families are angry and unwilling to remain passive," says Dr Fuller Torrey, a specialist in the management of schizophrenia. "They are going to lobby, protest and fight for help for those whose minds have been damaged."

One of the first of these protests took place a few weeks ago at the World Trade Centre in Manhattan. A group of 100 people, mostly women, dwarfed by the twin towers, waved crude home-made banners and collected signatures for a letter of protest to Governor Cuomo of New York State.

"We made history," said

their organizer, Isabelle Blau, a brave woman, divorced, who works in a department store. "This is the first time there has been a protest in New York on behalf of the mentally ill."

Her large, sad eyes betray the years of anguish as she watched first one, then a second son, destroyed by schizophrenia. The older boy, now 38, went to Israel hoping that work on a kibbutz would cure him. He has been in mental hospitals for years and his mother spends her three-week holiday each year visiting him.

Frustrated by her experiences, she decided on stronger action. "The parents are too polite," she says. Typing on her old portable, she sent letters to other parents.

Soon there was a core of would-be militants. Two of her aides are Rita Kwiecinski and Rose Lange, ordinary, working-class women prepared to fight hard for their mentally-ill children. "Governor Cuomo will hear more from us," they say.

So will many other politicians, for another centre of direct action over schizophrenia is on Capitol Hill itself. The wives of six Congressmen, some of them mothers of schizophrenics, have joined together to lobby for a better deal for the mentally ill. "Every time you look at a tramp or bum, you think that this guy had a mother," says Norma Lagomarsino whose husband, Robert, is Representative for California. "It's the women who live with it who are on the

move. They are becoming more organized."

Norma Lagomarsino is the most outspoken of the Capitol wives and describes how her son became ill when he was 16, hearing voices and believing people were trying to destroy him. For 12 years he was in and out of hospital. "He began to get better when we realized he had an illness and once his father accepted he was not lazy or pretending," she says.

"When we all realized it was some chemical malfunction for which no-one was to blame, he accepted the illness and the medication. It's just like diabetes. You develop a way of dealing with it and not concealing it."

Nancy Domenici is the wife of Senator Peter Domenici of New Mexico, and mother of their eight children, one of whom is disturbed. She has organized the lobbying wives from her home in Rockville, Washington. She arranges lectures on mental illness for the politicians on Capitol Hill, and has written to the committees responsible for setting budgets, asking for more money for research into mental illness.

"The thing that convinced me to speak out," says Norma Lagomarsino, "was the assassination attempt on President Reagan by a schizophrenic. Our son was in hospital at the time. But there were hundreds of mothers who did not know where their disturbed sons were and feared it could be them."

Can families handle schizophrenia alone or could old as

Mad, bad or simply sad?

What can parents do when a grown-up child tyrannizes them but refuses to accept their love? Should society wait until a crime is committed — or someone dies — before it takes action?

Marjorie Wallace investigates

THE TIMES 29 OCTOBER 1986



Michelle's mother, Sheila, spends bleak days agonizing over her exiled daughter

Michelle is a beautiful 25-year-old girl, well-educated, and much loved by her family. Her father, Brian, is a professional man in a north London practice. Her younger brother, Richard, is a student. Her mother, Sheila who is extremely close to her daughter, keeps house for the family.

But Michelle is not allowed to visit. In fact, the family have set her up in a flat of her own and taken out an injunction to keep her away. For her dependence on her mother is so strong that she can live neither with her nor without her. Michelle has assaulted Sheila on several occasions, hurting her quite badly.

Brian and Sheila are caught in a tragic double bind: the more they try to help their daughter, the more helpless they become. Doctors, psychiatrists and counsellors advise them that they must sever contact with Michelle, while neighbours, police, even complete strangers who find her in distress, accuse them of neglect and beg them to take her home.

Sheila now spends bleak days and nights agonizing over what has happened since Michelle first began to act strangely eight years ago. She dreads the sound of the telephone, knowing it will be another cry for help from the exiled, tormented girl, so the family uses an answering machine to intercept the calls. Earlier this month Brian was up early and played back the tape.

"Dad, it's me. I don't feel very well. I don't know what to do. I've gone insane and everything. I need you and Mum very badly. Tell me what to do. I want to come home. You've got to pick me up straight away." It was Michelle's usual kind of message — anguish mixed with threat and manipulation. A second message followed, more pathetic than the first. "I'm not crying or anything, I'm just a bit worried. I can't carry on."

An hour later, while

Brian was dressing upstairs, there was a crash of splintering glass. He ran down to find Michelle climbing in through the shattered living room window. Richard, who was breakfasting downstairs, guessed what would happen and rushed upstairs to protect his mother by locking her in her bedroom. Sheila rang the police.

Michelle calmed down, made herself a cup of tea and went to look at her old room, now sad and empty, because her bed and all her possessions were transferred to the flat. A few minutes later the police arrived and took her to Hendon Magistrates' Court to be bound over to keep the peace. Brian knew she would be released and sent back to the flat, just as depressed as before and without receiving the help she needed. In despair he decided to apply for a summons for criminal damage.

"It's a terrible thing to take out a summons against the child you love with all your heart," he said. "But she has been in and out of hospital for seven years. No treatment worked. She is getting no medical treatment now. We need help."

As he pleaded with the magistrates in one of the court rooms, Brian could

hear his daughter's screams resounding from the cells. But his efforts proved unnecessary. Michelle refused to agree to the terms of being bound over and was sentenced to three weeks' imprisonment in Holloway.

Two weeks ago, she was released. The prison psychiatrist, Dr Edgar Unwin, told the parents that he did not find her sufficiently ill to make an order to send her to hospital compulsorily, and because throwing a brick through a window was not a serious offence, they could not detain her any longer. Arrangements were made for her to go to Shenley Psychiatric Hospital, Hertfordshire, but the staff were reluctant to have her back (she had taken herself in and out of there three times in the previous month). On the morning of her release from prison, the family were told that a mistake had been made and no bed was available at the hospital.

So within hours Michelle, carrying her suitcase, was back outside her parents' house shouting, and banging on the door. The on-

slaught became more furious. "I'm your daughter. You must let me in," she screamed.

"At first she didn't know we were there," Sheila says. "We park our cars around the corner and hide when she comes. Then everything went quiet and I thought she had left. Then I heard a letter come through and crept to pick it up. My eyes met hers through the letter box." When she realized that her mother would not open the door, Michelle rushed into the road and lay down. Sheila and Brian, knowing that they could not help, had to watch from a window as the cars swerved round her. She was dragged back by passers-by and after the police arrived, she wandered away, a forlorn figure.

"I just longed to run out and hug her," Sheila says. "But she would only attack me again."

Last week Brian tried to break the stalemate by invoking a summons for breach of the injunction on Michelle returning home. But the local social services intervened, threatening to withdraw offers of help in

financing a place in a hostel and closing their books on the family. "We had no alternative but to forget it," Sheila says. "The social worker condemned me for trying to get my daughter into Holloway. They don't realize how desperate we are. It is our only chance of getting medical reports."

Michelle was a slight, shy girl of 17 when she first showed signs of mental instability. "We were having a family Sunday lunch," recalls Sheila. "Michelle ran upstairs to her room, screaming with a pain in her head. She was breathing fast and looked as though she were in a fit. We called a doctor who sedated her." From then on Michelle behaved strangely, sometimes haranguing her mother and at other times following her around like a frightened lost child. "Sometimes I would find her curled in a corner of the room like an embryo," Sheila says. "Mummy, mummy, do you love me?" She would ask again and again but when I reassured her she would kick and punch me."

Michelle was taken to a series of psychiatrists, each referring her on to a colleague, and she became a patient in several psychiatric hospitals. She has been diagnosed variously as suffering from "endogenous depression", "phobic anxiety", "identity crisis" and "episodic discontrol". In the last eight years she has been treated with anti-psychotic drugs, anti-depressants, and electric shock therapy.

In desperation her parents arranged private clinics, but she would always run away and no one was prepared to detain her. "We couldn't drive her back because she would try and throw herself out of the car or grab the steering wheel,"

says Brian. "We had to pay for private ambulances to take her back and then, sometimes in a few hours, she would be out again, ringing us from some station."

In February 1984, Michelle was admitted under a six-month's hospital order to Spyways adolescent unit for behaviour modification. Even Spyways (which was later closed for its use of "controversial methods") made little impression. By the end of the year, she was admitted to the Bethlem Royal Hospital near Beckenham, Kent, and was diagnosed and treated as a schizophrenic. Michelle showed no change and her behaviour on weekends at home became even more disturbed. "We couldn't hold a rational conversation with her," Sheila says. "If you took her shopping or to a restaurant she would make a scene and have to be removed."

Just before Christmas last year, Barnet General Hospital, where Michelle was now a patient, withdrew medication and she seemed to improve. In a final bid for normal life, Michelle and her parents signed a "contract" of reasonable behaviour and she returned home. But within days, the contract was broken and this time it was Sheila who was taken to hospital in a state of collapse. On Christmas Day Michelle was made to move into a flat of her own.

Her parents know that she cannot cope. She has no friends and her illness makes her unable to attend out-patients or to accept help. Four GPs have already banned her from their lists and at the end of this week, she is being rejected again. "So far we have been unable to help her in a constructive and meaningful way," they wrote to her parents, "and we are not very optimistic about our ability to do so in the future." All the hospitals in north London have refused to readmit her. Three hostel places have fallen through because of her behaviour.

"There is nowhere for her to go," her father says. "We bought her this flat but she pesters the neighbours and the manager is asking me to evict her."

The social services, with their emphasis on civil liberties, have taken little notice of the parents' plight. "When we saw her, Michelle was not a danger to herself or others in our presence," they wrote, explaining their reluctance to section her to hospital.

Sheila is bitter about the lack of compassion from the doctors and social workers. "They tell us to cut her off, that she is drowning and will pull us down with her. But we can't have a moment of pleasure without feeling guilty, knowing she is in despair."

It is Michelle's own protection that Brian and Sheila are seeking. "The Holloway psychiatrist told us they could provide no further medical help until Michelle commits a serious crime — which he thinks is quite on the cards," Brian says. "All we can do is wait."

THE HOLE IN BRITAIN'S SAFETY NET

The professionals offer little hope for Michelle and her family. She falls between all the labels and therefore slips through the medical and legal constraints. She is not suffering from a recognized mental illness, is not mad enough to warrant sectioning to hospital, nor has she committed any crime.

"She is in grave danger to herself and others at this time," says Henry Meyer, a retired mental welfare officer who is befriending the family.

Hospitals will not admit her because they do not like disruptive patients. One psychiatrist said that, since she is likely to commit suicide, this limited time is better spent on more treatable cases. Social workers have to choose in whom to



Happier times: Michelle and Sheila

invest resources. While she is roaming around, there is no one who can find, let alone help her. She needs to be contained.

"Every psychiatrist sees a number of people like this," says Anthony Clare, Professor

of Psychiatry at St Bartholomew's Hospital. "They are not suitable for hospital or prison. They are very unhappy, self-destructive people. The only comfort is that as they grow older, the drive depletes and by the time they are 40 years old, they will settle down."

Robert Buglass, Professor of Forensic Psychiatry at Birmingham University, is also pessimistic. "Society has done nothing for people who do not fit the categories," he says. "It all comes down to resources. Many of them would be better off in small highly-staffed specialist units. The nearest we have are the medium secure units, but they are only now being built. It is a fine balance between the liberty of the individual and the protection of the public."

ylums be adapted to become a home-away-from-home?

Taking the people to the patients

A Victorian mental health asylum could be turned into an Italian-style town, with the patients still at its heart, thanks to an architect's imaginative plan. Marjorie Wallace reports

When Claybury was built in 1893, it was something of a showpiece, an asylum devoted to the care of the mentally ill, with its own ornate theatre and church seating 2,500 patients, its laundry and workshops and a 300-acre farm and orchard. It was planned to be self-sufficient. Lavishly designed, it was a memorial to Victorian guilt about madness.

It had been built originally on wooded slopes 230 feet above the open Essex countryside, 10 miles north-east of London. Today its water tower and imposing chimney dominate the surrounding sea of drab and featureless suburbs. The hospital, now ageing and slightly forlorn, is expensive to run. Its formal landscaped gardens have been turned to grass; its Victorian Gothic pavilions are patched with incongruous modern extensions. Its farm is derelict and most of its patients have gone.

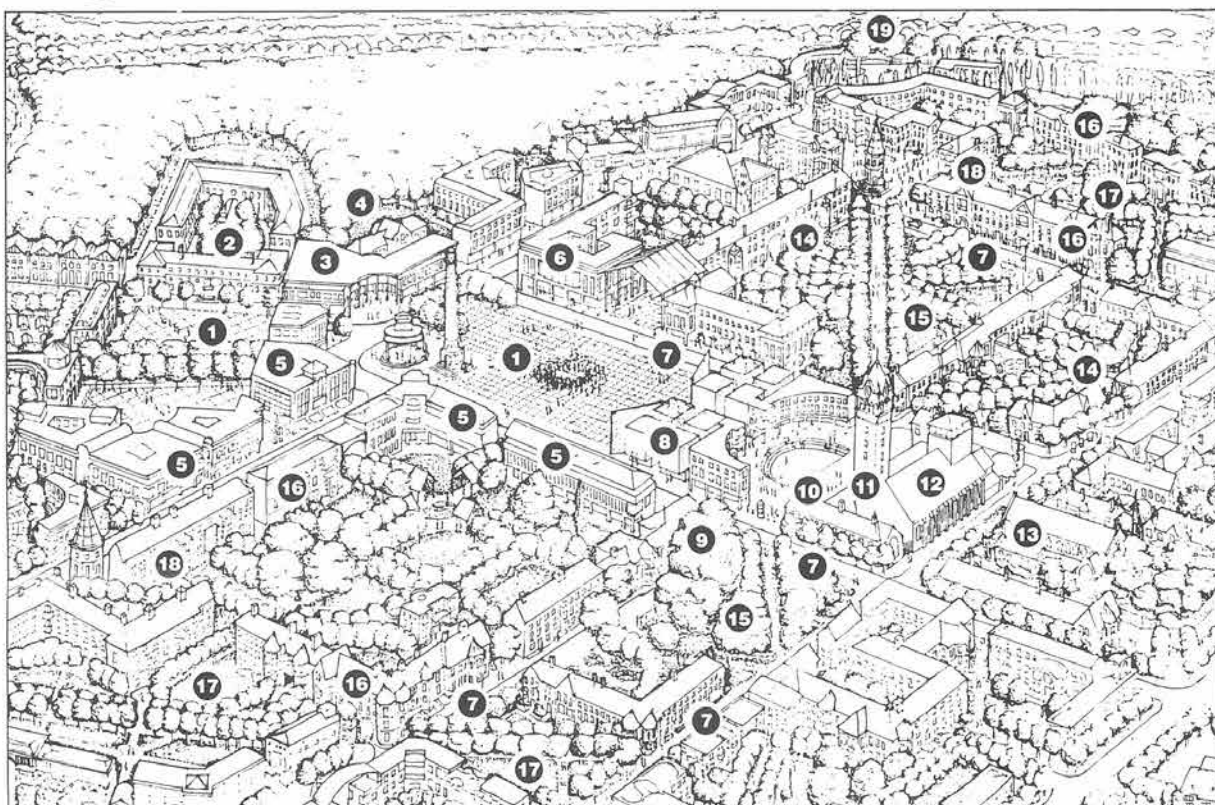
Thirty years ago there were 2,300 people living here; now there are 800. The exodus, which began in the late 1950s with the discovery of neuroleptic drugs, is accelerating as a result of government policy to return patients to the community. In 1993 Claybury will be closed.

But what's to be done with this Victorian hilltop town when it finally shuts its doors? What will happen to the 300 patients still in need of continuing care?

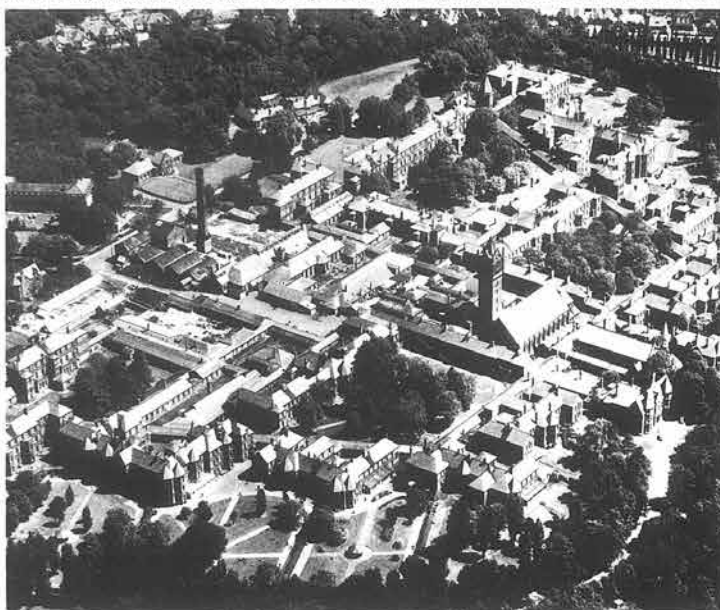
John Burrell, a 39-year-old community architect who lives in London, grew interested in Claybury after studying Victorian asylums, and believes he has found the answer. He sees Claybury as the capital of the suburbs it surveys — almost like an Italian hilltop town. Within the sturdy walls of the Victorian buildings it could contain shops, a leisure centre, offices, flats and houses.

The water tower would be fitted with a clock and become the "cathedral" of the new city. Beneath it, a busy piazza would serve as the town centre, with cafes, ice-cream kiosks and buskers on the steps of what used to be the boiler room chimney. There would be fountains, walkways and shops built on the gallery principle. The old asylum theatre would be retained as part of an entertainment centre with an amphitheatre and cinemas. The old "airing courts", or exercise yards for the patients, could be converted into smart urban squares. The 200-acre site would house about 3,000 people.

But Burrell's idea goes further than simply re-using a heritage of elegant and well-constructed buildings. He proposes to find room within the site for a 40-bed short-stay hospital for mental



John Burrell (left) under the tower he hopes to convert. His visionary scheme (above) would breathe new life into the hilltop Claybury asylum (below)



- 1 New public squares, shops, banks, cafes, library
- 2 Former nurses' home integrated and converted
- 3 Health administration building
- 4 High-dependence accommodation
- 5 New retail building
- 6 New office building
- 7 New streets created
- 8 New cinemas
- 9 New day centre
- 10 New open-air arena space/square
- 11 Existing water tower adapted as clocktower
- 12 Assembly hall adapted to local theatre
- 13 Existing chapel in new setting and grounds
- 14 Sheltered housing
- 15 Existing landscaped airing courts improved as public and private gardens
- 16 Typical residential accommodation, private, public, housing association
- 17 Existing paths linked to form pedestrian routes
- 18 Special hostel as part of ordinary terraced housing
- 19 One of the new high street connections to local streets

patients and flats and hostels for the 300 long-stay patients. He plans that their accommodation should look out over the "airing courts", which would become their private and secluded gardens.

"The Victorians believed that these hospitals were a humane way of protecting mad people from the stresses of normal life," Burrell says. "They also thought they could stop mental disease spreading by fading out reproduction among the unfit." The female wards were on one side of the hospital, the male on the other. Between them were the central services: the theatre, the kitchens, the laundry and the church. But men and women entered these places, including the church, through separate entrances. Even in the mortuary (planned to become a tea room),

the same principle applied: separate rooms were provided for male and female corpses.

John Burrell's main challenge was to convert this inward-looking hospital from a "pseudo town", rather like the large monastery of a closed order, into a town which could reach out into the world around it. His vision is to replace the corridors by roads, to create courtyards, to provide archways, while retaining the intimate urban relationships of the buildings.

This is more than an architectural Utopia. The alternative is to sell the site to developers and rehouse the long-stay patients elsewhere in the community. But Waltham Forest, the area health authority, is already encountering opposition from local residents to such a proposition.

The great advantage of Burrell's scheme is that it brings the community to the patients — "and since the patients are there first," he points out, "the newcomers can't object."

Luxury houses have already been built right up to Claybury's boundary fence.

"You can imagine the opposition there would have been if those houses had been there first and we were trying to get planning permission to build this hospital."

The principal could apply to many other mental hospitals of similar size. Bexley, Goodmayes, Hill End, Horton, Manor, Menstone, Netherne, Severalls, Swansea and West Park — all have the potential to be developed as city centres.

Burrell's ideas are being taken seriously by several health

authorities, including Leicester, which has commissioned a study. During the last few years while hospitals have been running down, many acres of valuable land and buildings have been sold piecemeal to developers and the proceeds have disappeared into the health authorities' general funds. When this happens the mentally ill do not necessarily benefit, despite the Department of Health's assurances that they will.

The Claybury scheme was recently presented at Westminster, where it attracted interest among the Commons all-party mental health group. "It is an exciting and novel scheme," says Nicholas Winterton MP, who is fighting for the rights of discharged mental hospital patients.

Professor Kathleen Jones, of York University, the leading expert on the social care of discharged mental patients, is also enthusiastic. "You'll get executives living there. It will be so upmarket, the stigma will be removed from mental illness," she says.

"You can't plant patients into the community like currants in a bun. On this scheme they would be there from the beginning. There could be a whole range of places for them, from flats where they would be totally independent to group homes where there would be staff on duty day and night."

John Burrell conceived his idea when he saw a derelict mental hospital in Trieste. There were squatters and rats. "I would hate to see that happen in this country," he says.

The campaign goes on

"The Forgotten Illness" kindled an almost unprecedented response. Hundreds of letters to *The Times* demanded something be done. The outcome was SANE and a continuing campaign for awareness, providing care and initiating research

SINCE *The Times* ran its original "Forgotten Illness" campaign, SANE has become the most vocal and the fastest growing mental health charity in the country. The almost unprecedented numbers of letters to the Editor (some of them are reprinted on page 11) caught us by surprise, indicating that the neglect of schizophrenia was a greater disaster than even we believed.

We now have evidence of just how serious it is, for SANE's helpline. SANELINE had 100,000 telephone calls in its first year of operation, providing information and help to sufferers and their families trying to cope with mental illness.

SANE continues to campaign and to make the news. During 1993 the charity generated over 300 media items and interviews, many of them in the national and international press. SANE's high profile not only brought awareness to the general public of the widespread neglect of serious mental illness, but it has made sufferers and their families aware that SANELINE can help them.

Since starting SANELINE, SANE has widened its

concerns to all serious mental illnesses. Otherwise, its three aims remain the same:

- **Awareness** - to campaign for greater understanding and awareness of serious mental illness;

- **Care** - to pioneer care projects, such as SANELINE, and other ways of helping sufferers and carers;

- **Research** - to initiate medical research into the causes, treatment and eventual cure of serious mental illness.

SANELINE is the largest of the care projects. It opened on 29 April 1992 and proved an immediate and overwhelming success. The calls are taken by an army of 120 volunteers, which it is hoped to increase to more than 200 over the next year to meet the rising demand.

The vision of SANELINE was that it should provide callers with practical information to help them when things seem hopeless and to show them new options and ways ahead.

Every volunteer receives a minimum of 35 hours training before he 'passes out' and is allowed to work on the helpline. Even then, the learning is not over, as all volunteers take part in an on-

going training programme.

At the time of writing SANELINE is open from 2.00 pm to midnight every night of the year. Each SANELINE shift is supervised by one of six (soon to be increased) paid coordinators, who are responsible for maintaining the quality of the service.

Finally, there is SANELINE's 'secret weapon', a unique computer database which contains details of 12,000 mental health resources in every part of the country. The volunteer keys in the callers town and details of local services appear on a screen.

Anyone who has spent even a few hours with someone suffering from schizophrenia will know the sufferer wants to be released from the tyranny of his symptoms. Although there are now a number of antipsychotics which may control more serious symptoms, current treatments are not cures, and fail in 25% of cases.

The time is propitious for SANE's third aim because the blossoming of biological science over the past 30 years is now at the point where scientists are beginning to

understand how the brain works and what goes wrong with it. See, for example, "Cracking the Mind's Secrets" (page 8) and "Scanning the brain in search of a cure" (page 4). To take advantage of this SANE's professional advisers have decided to set up an applied research centre as part of Oxford University.

The Prince of Wales International Centre (POWIC for short) will be able to transfer concepts and technologies from the 300 brain scientists working in Oxford, the largest concentration in Europe. POWIC will be sited near a psychiatric hospital, so it can make the link between scientific discovery and the mentally ill patient.

POWIC will be a £5 million project in its first stage, and much of that money has already been contributed by King Fahd of Saudi Arabia, and by the Greek shipping family Xylas, through Matti and Nicholas Egon. Oxford University has made a generous donation, and the Medical Research Council is supporting a large part of the first research programme. Still more money is needed for further research projects.

The campaign must go on!

SANE'S CHIEF EXECUTIVE

Marjorie Wallace is an award-winning journalist, author, playwright and broadcaster, and has won nine major awards for her journalism, books and plays, including the Campaigning Journalist of the Year Award (twice) for her "gift of combining great compassion with objectivity" and then for her "outstanding" work on schizophrenia. She won the Snowdon Special Award for her 15 years work with disadvantaged people.

She graduated in philosophy and psychology at University College, London, and then worked in television for the Frost Programme and later as a reporter, film director and documentary producer for both ITV and BBC.

In 1972 she joined the Insight team at *The Sunday Times* exposing the Thalidomide tragedy, and was co-author of "Suffer the Children" and "On Giant's Shoulders", the story of Terry Wiles. The BBC film, based on her original screenplay, won the International Emmy Award for the best drama in 1979 and was selected as one of the five best plays for the BBC's 50th Anniversary. She also wrote the book and subsequently the screenplay for "The Silent Twins" (BBC 2) which was nominated as the BBC entry in the Monte Carlo Television Festival 1986. Oliver Sachs described the book in the *New York Times Review of Books* as "a remarkable and tragic story which in its depth, penetration and details, no less than its extraordinary subject



Michael Ward

matter cannot but be seen as outstanding... a testimony to something extraordinary in the author herself".

In 1988 she wrote and presented a Byline film "Whose Mind Is It?" which exposed the terrible neglect of sufferers from schizophrenia and their families. In 1994 she presented a further hour-long documentary "Circles of Madness", challenging the received wisdom about community care and civil liberties.

The Daily Telegraph described Marjorie Wallace as "a human dynamo... an astute fund-raiser who fully appreciates the power of publicity". In 1993 she appeared 300 times on TV and radio current affairs and news.

In 1989 she was awarded the Guardian Fellowship at Nuffield College, Oxford and published the results of her research in a lecture and

pamphlet: "Campaign and be Damned!"

She is currently Chief Executive of SANE, the mental health charity, which she helped found in response to her series of articles in *The Times*: "The Forgotten Illness" (1985-6) reprinted here. HRH The Prince of Wales said of her work: "There are shining examples of what can be done, such as a series of articles by Marjorie Wallace, which not only laid the contemporary understanding of schizophrenia but also led directly to the foundation of SANE, of which I am Patron."

Since she became Chief Executive in 1989 she has helped raise more than £10 million, launched two major projects (SANELINE, a pioneering telephone helpline for people coping with mental illness, and the Prince of Wales International Research Centre), seen SANE's income increase threefold and staff increase from 6 to 28 people with 140 volunteers.

She is Chairman of the Friends of The Open Air Theatre; a member of the Board of Management of the Institute of Psychiatry; a member of the Institute of Psychiatry Ethics Committee (Research); and other bodies.

Marjorie Wallace (Countess Skarbek) is married and lives in London with her three sons, Sacha, Stefan and Justin, and her daughter Sophia Augusta.

SANE'S INTERNATIONAL VICE-PRESIDENTS

Seven world figures from science join the international fight against mental illness



PROF WALTER GILBERT was awarded the Nobel prize for chemistry in 1980. He is a physicist and molecular biologist who holds a Chair in cellular and developmental biology at Harvard University. In 1960 he worked with James Watson on messenger RNA. He now works on protein synthesis and DNA sequencing.



SIR RAYMOND HOFFENBERG, born 1923, qualified as a doctor at the University of Cape Town. He came to Britain in 1968 after being banned by South African government. In 1972 became Professor of Medicine in Birmingham. President, Mental Health Foundation. Now at University of Adelaide.



PROF RITA LEVI MONTALCINI won the Nobel Prize for Medicine in 1986. In 30 years of study, divided between Washington and Rome, she discovered the Growth Factor - key to the immune system. Guest Professor at Italian National Research Council, she has revolutionized concepts in nervous system functioning.



PROF GIORGIO RACAGNI is Professor of Pharmacology and Director of the Centre for Neuropharmacology, Milan University. President of CINP, author of over 250 papers and Director of the WHO Centre for Research and Training in Mental Health. Vice President of the World Federation of Societies of Biological Psychiatry.



DR NORMAN SARTORIUS, a native of Zagreb, is consultant to the WHO and Professor of Psychiatry at the University of Geneva. Author of 200 papers including comparative studies of schizophrenia, which have shown that its incidence is the same (1 in 100) across the world, suggesting that environment was not the cause.



PROF SOLOMON SNYDER is a world authority on the chemistry of mental functioning (notably receptors and the drugs affecting them) and author of 7 books including "Madness and the Brain." Winner of over 30 awards, he is Director of the Neuroscience Department at John Hopkins University School of Medicine.



DR E FULLER TORREY is a research psychiatrist at the NIMH Neuroscience Centre at Washington DC. His studies of schizophrenia have taken him from Ireland to New Guinea and he is currently studying identical twins. A notable author and communicator, he appears regularly on US national television.

Patron: HRH The Prince of Wales

Chairman: The Lord Mottistone
Directors: Sir Campbell Adamson
John Baker

Charles Bracken
Sir Bryan Hayes
Sir John Riddell
The Lady Waddington
Ian Hay Davison
Rob Matthews

Chief Executive: Marjorie Wallace